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LAURA TAYLOR-ROBERTS MA (Hons)

**MEASURING THE COMMUNITY PARTICIPATION OF ADULTS WITH
INTELLECTUAL DISABILITY: DEVELOPMENT AND VALIDATION OF
THE GUERNSEY COMMUNITY PARTICIPATION AND LEISURE
ASSESSMENT-REVISED**

Section A: A Review of Community Participation Measures for People with
Intellectual Disability

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Church University for the degree of Doctor of Clinical Psychology

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY
April 2017

Assessment cover sheet

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DECLARATION FOR MAJOR RESEARCH PROJECT

Candidate name ...LAURA TAYLOR-ROBERTS.....
(PRINTED)

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

SignedLaura Taylor-Roberts.....
(candidate)

Date27th November 2016.....

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

SignedLaura Taylor-Roberts.....
(candidate)

Date27th November 2016.....

Signed 
(supervisor)

Date28th November 2016.....

STATEMENT 2

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Signed Laura Taylor-Roberts.....
(candidate)

Date27th November 2016.....

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I would like to express my gratitude to my supervisors: Dr Fergal Jones and Dr Peter Baker. They have provided support and understanding as well as expert supervision and encouragement. I would also like to thank Sabina Hulbert for her statistical consultation.

Finally, I would like to thank my family and friends for their support and compassion. Thank you especially to my parents and Eddy and Ottilia.

Overview of the Major Research Project

Section A introduces issues related to the measurement of community participation in adults with intellectual disabilities. The review identifies and critically examines such measures. The psychometric properties of ten measures of community participation are presented. Outcomes regarding the validity, reliability and interpretability of the measures are examined with future clinical and research implications discussed.

Section B consists of an empirical investigation to explore the use of the GCPLA-R questionnaire with adults who have an intellectual disability. An initial focus group and consultation stage uses qualitative methods, taking on a discovery-oriented approach. The questionnaire is then updated and revised to produce an up-to date measure with appropriate content. This is then tested across a large provider of services for adults with intellectual disabilities in the South East. Factor analysis is performed and psychometric properties are obtained. Part B concludes with a discussion around limitations and implications.

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Laura Taylor-Roberts BA (hons)

**Section A: A Review of Community Participation Measures for
People with Intellectual Disabilities**

SALOMONS
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Church University for the degree of Doctor of Clinical Psychology

ABSTRACT

Objective: To identify and critically evaluate measures of community participation designed for adults with intellectual disabilities. To examine the content and psychometric properties, highlight limitations and provide guidance on the selection of community participation measures.

Method: Two systematic searches were performed across eight electronic databases; the first to identify measures of community participation and the second to identify validation studies for each measure. Measures were included if they were developed for adults with intellectual disability, measured extent of participation and had published information regarding content and psychometric properties. Ten measures were selected, with 27 papers reporting psychometric information. Each measure was evaluated on the basis of psychometric properties and in relation to coverage of nine domains of community participation from the International Classification of Functioning, Disability and Health (ICF).

Results: Three measures were 100% composed of community participation items. The remaining measures contained between 30.0% and 94.4% community participation items. The ICF domain coverage was between 3 and 7 domains for each measure. The quality ratings varied from 2/16 to 12/16.

Conclusions: The majority of measures were not sufficiently psychometrically tested and no measures had undergone factor analysis. Findings suggest a need for the development of a psychometrically robust instrument.

Introduction

Definitions

Intellectual disability originates before the age of 18 and is characterized by significant limitations in intellectual functioning and adaptive behaviour, covering many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities; AAIDD, 2016).

In terms of community participation, this review will use the definition given by Chang, Coster and Helfrich (2013). Using The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) definition of participation ("involvement in life situations") as a starting point, Chang et al. define community participation as:

"active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role" [p. 772].

This definition was chosen due to its basis within the ICF and its acknowledgement of non-domestic roles within the home.

Community participation and quality of life

Schalock, Verdugo and Braddock (2002) identified eight dimensions of Quality of Life (QoL), which were validated in a series of cross-cultural studies (e.g. Schalock et al., 2005). Jenaro et al. (2005) highlight that 'community integration and participation' is one of the three most commonly referenced published indicators for

the domain of Social Inclusion. Schalock, Bonham and Verdugo's (2008) QOL conceptual framework categorises the eight domains into three factors; independence, social participation and well-being. It is clear that social/ community participation is acknowledged as an important indicator of QoL.

As highlighted by Verdonshot, de Witte, Reichrath, Buntinx and Curfs (2009), theoretical models of human functioning such as the Disability Creation Process Model (Fougeyrollas et al. 1998), the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), and the Theoretical Model of Intellectual Disability (ID) by the AAIDD (Luckasson et al. 2002), all include community participation as a fundamental aspect of human functioning. The ICF's identification of various domains of community participation is discussed in detail within the quality criteria of this review.

Community participation can be considered a 'process by which other goals are achieved' (Myers, Ager, Kerr & Myles, 1998; Emerson, 1985, p. 280). Research has shown that participation in community and leisure activities by people with ID improves their perception of quality of life as well as encourages their inclusion in the community and contributes to the acquisition of adaptive skills (e.g. Cummins & Lau, 2003).

Measurement of community participation

It is clear that policies and procedures should include the facilitation of community participation in the daily lives of people with ID. It follows that an accurate measure of community participation is needed in order that services can identify support requirements and monitor participation.

Verdonschot et al. (2009) report broadly that instruments measuring community participation among adults with ID were often ad hoc and unvalidated. Chang et al. (2013) conducted a meta-analysis of community participation measures for people with disabilities, looking specifically at their content and ICF domain coverage. Amongst the 17 measures reviewed only four were designed for people with ID. However this was not exhaustive of the measures available and psychometric properties were not examined. This highlights the need for a comprehensive review of community participation measures for people with ID.

Aims

This review will be narrative in nature, and based on a systematic search. The aim is to describe and critically evaluate the available measures of community participation for adults with ID. To the authors' knowledge, this is the first review that critically examines the psychometric qualities and content of such measures developed for this population.

Methodology

Inclusion/Exclusion criteria

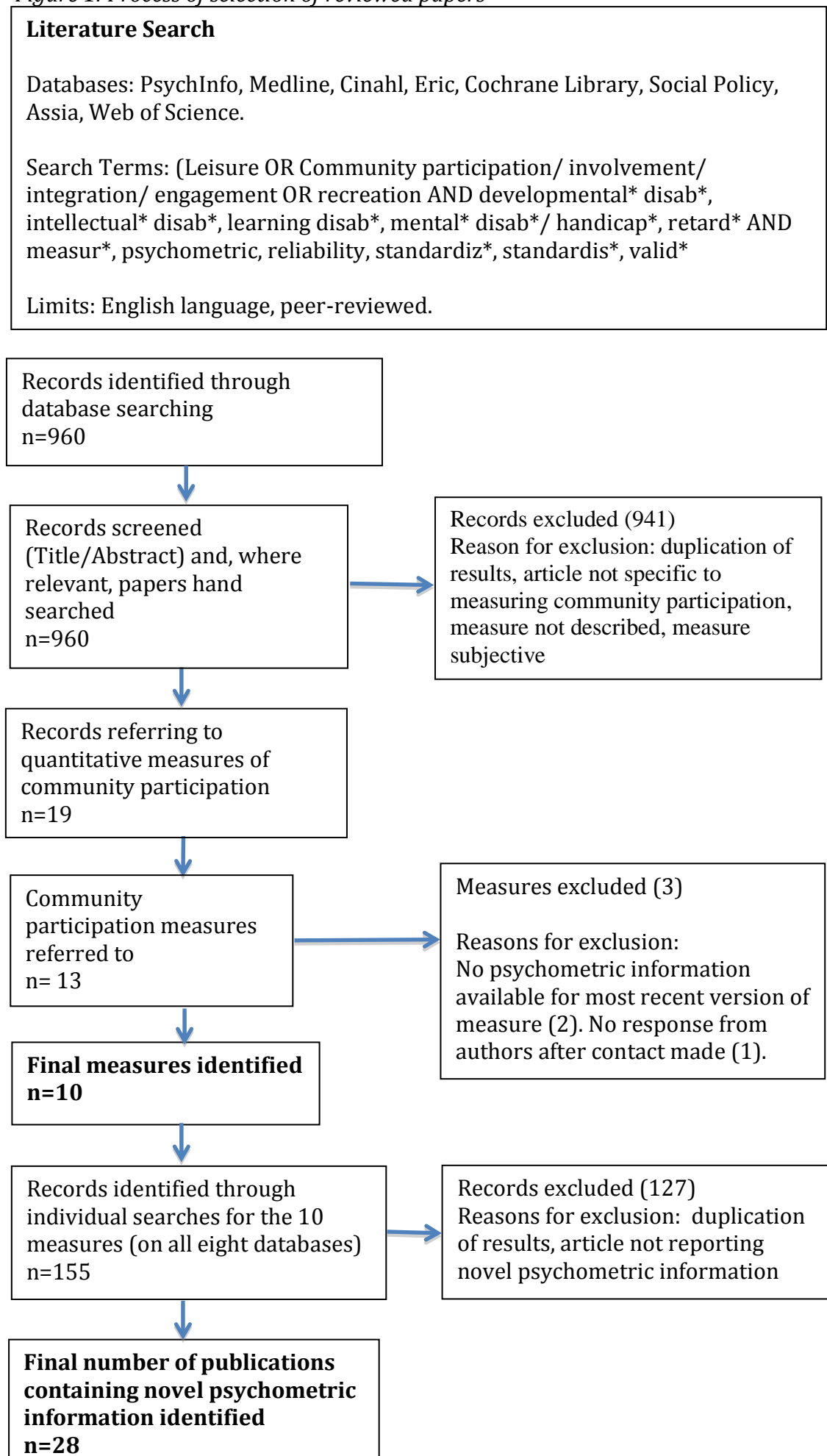
Community participation scales can either measure the amount/ frequency/ variety of community participation or the experience/ satisfaction with/ impact on wellbeing of community participation. Whilst the latter can provide insight into meaning and internal experience, the former can provide quantifiable, standardized information to detect change or compare with other settings/populations (Chang et al., 2013). This

review will focus on the level of community participation. Measures focusing entirely on experiential aspects of community participation will be excluded. This review will focus on measures that have published findings on their psychometric properties and have been reported in at least one peer-reviewed journal in English. Measures that were not developed for adults with ID will also be excluded. Broader measures such as Quality of Life scales will only be included if they incorporated a quantifiable subscale devoted to community participation.

Information sources

The following databases were used to search for relevant papers: PsychInfo, Medline, Cinahl, Eric, Cochrane Library, Social Policy, Assia and Web of Science. Searches were performed from the date of inception of the databases until June 2015. An initial search was performed to identify measures of community participation. A hand-search was carried out based on the references of relevant papers found from the initial search. With the ten measures selected, a second round of searching involved searching the above databases for any further studies examining psychometric properties for each of the ten measures. Where papers were not available via databases, authors were contacted for full texts. Where measures were reported in publications but not freely available, authors/publishers were contacted for a copy of the measure. A full description of the search strategy and search terms can be found in Figure 1. Where relevant, the most recent version of a measure was reviewed. If the community participation items within a measure were confined to one subscale, then the subscale would be examined rather than the whole measure.

Figure 1: Process of selection of reviewed papers



Quality Criteria

Measures were rated for quality using an adapted version of Strauss et al.'s (2016) quality criteria. These criteria are a modification of Terwee et al.'s (2007) quality criteria for health status measures and include Barker, Pistrang, and Elliott's (2002) 'rules of thumb' for evaluating psychological measures. The trainee rated the quality of the scales using these criteria and discussed areas of uncertainty in supervision. In line with Strauss et al.'s (2016) guidance, measures were given a score of two if there was evidence for a criterion being fully met, one if the criterion was only partially met, and zero if the criterion was not met or if no relevant data were reported. Scores were summed to provide an overall rating. The total possible score for any measure was 16. If multiple authors had published conflicting information then the majority of published data needed to meet the quality criteria.

The quality criteria were as follows:

- Face validity. Each item within each measure was assessed as to whether or not it measured community participation as defined by Chang et al. (2013). Items that referred to activities very often done alone or at home were classified as not community participation. If an item included both community participation and non-community participation elements it was coded as "unclear". The number and percentage of community participation items were calculated for each measure. To obtain a score of two, measures needed to contain more than 70% community participation items. A score of one was given to measures comprising 60% community participation items.

- **Content validity.** The extent to which community participation was comprehensively sampled by the measure. Community participation items were classified into one of nine ICF domains of community participation: (1) assisting others (who do not live in the same household) (ICF domain code d660), (2) particular interpersonal relationships (d730-d779), (3) education (d810-d839), (4) work and employment (d840-d859), (5) economic life (d860-d879), (6) community life (d910), (7) recreation and leisure (d920), (8) religion and spirituality (d930), and (9) political life and citizenship (d950). Please see Appendix 1 for further information about these domains. Items that fit the definition of community participation but were not codable into any of the 9 domains (for example using public transport) were classified as “other”. For a score of two all nine domains had to be covered, and items had to have been generated in consultation with both experts and people with ID. A score of one was given if at least four domains of the ICF were covered.
- **Factor structure.** A score of two was given where exploratory factor analysis (EFA) followed by confirmatory factor analysis (CFA) were conducted or where CFA was shown to support a previously proposed theoretical factor structure. A score of one was given if only EFA was conducted (without CFA) and if the EFA supported the factor structure. A score of zero was given where either factor analysis was not conducted or where EFA and/or CFA were conducted and did not support a proposed factor structure.
- **Internal consistency.** To ensure that items in a (sub) scale were inter-correlated and thus measuring the same construct, factor analyses (or principal

components analysis) had to have been performed on an adequate sample size ($7 \times$ the number of items and $N > 100$) and Cronbach's alpha had to be between 0.7 and 0.95. A score of one was given if acceptable Cronbach's alphas had been calculated.

- Reliability. Test-retest reliabilities and (where relevant) inter-rater reliabilities had to reach $r = 0.70$ for this criterion to be fully met. For a score of one, one of these would be missing or the majority of coefficients do not reach 0.7.
- Convergent and discriminant validity. To test the extent to which scores related to other measures in a manner consistent with theoretically derived hypotheses, it was required that at least three quarters of results were in line with expectations. At least two correlations of at least $r = 0.50$ were required with theoretically related constructs in order to demonstrate convergent validity. A score of one was given when less than three quarters of results were as predicted or when only one correlation reaching 0.5 was reported.
- Floor and ceiling effects (i.e. the number of respondents achieving the highest or lowest possible scores). In order to attain a score of two, no more than 15% of the sample should have received the top or bottom score on a scale.
- Interpretability (the degree to which qualitative meaning could be attached to the quantitative scores and how differences in scores could be interpreted). Consideration was given to whether there is an indication of how scale scores

might be interpreted. For example whether normative data are available and whether possible subgroups were tested for differences.

Results

Relevant measures will be outlined and commented on and their psychometric properties examined. This will be followed by a critique and discussion of issues common to the measurement of community participation in adults with ID. Implications for future research will be considered.

Review of identified measures

Figure 1 depicts a flow diagram illustrating the search process. 960 papers were identified, with ten measures included after screening titles, abstracts, and full texts. Table 1 provides the psychometric properties of each measure. No studies included tests of discriminant validity, therefore this is not included in Table 1. Following Table 1, each measure is examined in further detail.

Table 1: An overview of psychometric properties

Measure	Face validity	Content validity: Domains of ICF captured (including 'Other')	Content validity: item generation (recipient and expert groups consulted?)	Internal consistency: Cronbach's alpha (for total scale and subscales)	Test retest reliability: r (time between testing)	Convergent validity: correlation (Pearson's r) with measures of related constructs	Floor/Ceiling effects	Interpretability: means and SD of scores of a reference population (norm values?) Subgroups tested for differences?
Life Experiences Checklist (LEC; Ager 1990, 1998)	30% community participation items	7	No	Total = 0.721	Total: r = 0.93, Subscales: r = 0.91 to 0.96 (one week) Reported elsewhere: Total: r = 0.721	Correlation with ICI of 0.78 pre-move and 0.72 post-move Correlation between LEC category of 'Leisure' and GCPLA category of 'Leisure, sport and recreation' of 0.74, and between LEC category of 'Opportunities' and GCPLA category 'Facilities/Amenities' of 0.55.	No floor or ceiling effects observable from the reference data. However not an intellectually disabled sample	Undergraduate students and general population Adults with ID: Institution and community living (scores were significantly higher after a move to the community)
Index of Community Involvement (ICI; Raynes, Pratt and Roses, 1979)	100% community participation items	6	No	Total = 0.85 (group) and 0.77 (individual) Reported elsewhere: Total = 0.59,	Reported elsewhere = 0.8	Correlation with LEC of 0.78 pre-move and 0.72 post-move Correlation with systematic observation of activity of 0.16 and	Not reported	Adults with ID. Residential setting: Institution and community living (scores were significantly higher after a move to the community) Adults with ID:

				0.689 and 0.62		0.20, $p < 0.05$		Older people's homes and ID homes (scores were significantly higher in ID homes regardless of whether people had an ID). Mean scores but not standard deviations are reported
Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000)	83% community participation items	7	Yes: Expert	Frequency scores = .93, Level of support scores = .82	Self report format: Range: $r = .87$, Activities alone: $r = .97$, Activities with peers: $r = .93$, Activities accompanied: $r = .96$, Very frequent activities: $r = .56$ (two weeks) By proxy format: Range: $r = .83$, Very frequent activities: $r = .84$, Activities with peers: $r = .8$, Activities alone: $r = .46$, Activities supervised: $r = .47$ (two weeks) Reported elsewhere: Range: $r = .72$, Very frequent activities: $r = .86$, Activities alone: r	Correlation with Adaptive Behaviour Scale: = 0.33 Correlation with three-week diary: 'Indoor leisure' = 0.652, 'Facilities/Amenities' = 0.737, 'Total score' = 0.682, Correlation between GCPLA 'Leisure, sport and recreation' and LEC 'Leisure' = 0.742, LEC 'Opportunities' and GCPLA 'Facilities/Amenities' = 0.552,	No floor or ceiling effects observable from the reference data.	Adults with ID and staff comparison (staff Range, Alone and Peer accompanied scores were significantly higher) Residential setting: Resettlement from hospital to community setting (Range scores were significantly higher after resettlement)

					=0.97, Activities accompanied: $r = 0.69$, Activities with peers: $r = .81$, Activities supervised: $r = 0.80$ (10-13 weeks)	Significant correlations between GCPLA range scores and Community Goal Rating Scale, ABS Part 1 and place of residence are reported without values. The three variables account for 38% of the variance in range scores ($F(3,56) = 11.37$; $p < 0.01$).		
Life Circumstances Questionnaire (LCQ; Ashman, Hulme & Suttie, 1990)	90.91% community participation items	7	Yes: Expert	Not reported	Not reported	Not reported	Not reported	Yes, adults with ID before, during and two years after resettlement from an institution, and separated according to whether participants moved to cluster centres or the community. Mean scores increased significantly over time and increased by a significant amount more for the participants resettled to the community.
Community Integration Scale (CIS; Heller & Factor, 1991)	83.3% community participation items	5	Unable to access original publication	Total = 0.80 at baseline and 0.79 at three-year follow up.	Not reported	Correlation with Adaptive Functioning Scale within ICAP: $r = 0.51$ (time one) and $r = 0.54$ (time two) Correlation with Decision Making	Not reported	Adults with ID and comparison sample of caregivers

					Reported elsewhere: Total = 0.57 at baseline and 0.85 at four-year follow up.				Scale = 0.74 Correlation with residential setting (nursing homes and community settings): r = -0.64		
TRIAL Leisure Assessment Battery (TLAB; Dattilo & Hoge, 1997)	60.6 % community participation items	7	No	Not reported	Activity patterns Relaxation Creativity Improveme nt and care Social interaction (home) Education Social Interaction Recreation Sports & exercise Entertainm ent & service Overall	Pas t .77 .87 .79 .82 .74 .72 .76 .76 .65 .78 No t rep ort ed	Current .75 .68 .80 .73 .34 .76 .39 .68 .53 .90	Not reported	Not reported	Adults with and without ID (scores were significantly higher for adults without ID)	
Leisure Assessment Inventory (Hawkins, Ardovino, Rogers, Foose & Olsen, 2002)	69.8% community participation items	6	Yes: Expert For the Spanish version two focus groups of adults with ID were consulted	Not reported	Leisure Participation Index: r = .55 (one year) Reported elsewhere: Leisure Participation Index: r = .84 (one year)			Correlation with Life Satisfaction Scale – Modified: r = 0.27 Correlation with GENCAT subscales: Personal Development: r = - 0.18 Self	Not reported	Adults with ID	

							<p>Determination: $r = 0.22$</p> <p>Social Inclusion: $r = 0.20$</p> <p>Contrary to expectation:</p> <p>Negative correlation with social communication skills: $r = -0.24$ and community living skills: $r = -0.26$ (Inventory for Client and Agency Planning)</p> <p>No correlation found with Integral Subjective Scale</p>		
Use of Community Facilities Scale (UCFS; Chou, Lin, Pu, Lee & Chang, 2008)	100% community participation items	4	No	Total = 0.81	Not reported	Adaptive Behaviour Scale (Taiwanese version) scores were a significant predictor of UCFS scores (Beta = 0.20, $p < 0.001$).	Not reported	Yes, adults with ID, according to residential status (mean scores significantly higher in small residential homes than in group homes or institutions).	<p>QOLQ scores were not significantly correlated with UCFS scores.</p>

Community Participation Inventory (CPI; Stancliffe & Keane, 2000)	100% community participation items	5	No	Number of places used = 0.54 Frequency of use = .21 Number of places used without support = 0.73	Not reported	Not reported	Not reported	Group mean scores are reported. Standard deviations are not reported. Scores for Frequency and Number of places used without staff support were significantly higher for participants living in semi-independent settings than those living in group homes
Six Monthly Interview Schedule (6MIS; Lowe & de-Paiva, 1988)	94.4% community participation items	2	No	Not reported	Test-retest reliability is reported as percentage agreement: 97.4%: range 89.5-100%. (3 months)	Not reported	Not reported	Not reported

The Life Experiences Checklist (LEC; Ager 1990, 1998)

Description

- Self-report or informant-report
- Five domains: Home, Leisure, Relationships, Freedom and Opportunities.
- Items are scored as 1, if they are experienced, or 0 if they are not. The total possible score is 50.
- Only the domain of ‘Leisure’ consists entirely of community participation activities. The items vary from “I have a hobby or interest” to “I do some sport at least once a month”.
- Other domains contain some items relevant to community participation such as “I vote in elections” but also contain items indicative of broader quality of life such as “I choose my own clothes”.
- The LEC includes items based on personal experience such as “I feel loved and accepted by those who live with me”.
- Three additional published papers reporting novel psychometric analysis of the LEC were found.

Reliability

Ager (1988) reports a test-retest reliability coefficient one week after initial administration of 0.93 for total scores, with subsection scores ranging from 0.91 to 0.96. However the participants (n=20) were self-reporting undergraduate students rather than people with ID. Ager additionally reports the unpublished findings of Look (1987) with a sample (n=48) of “hospital residents” with a “range of handicap”. Ager reports that Look found an inter-rater reliability coefficient of 0.8 (n=10), although one rater scored consistently higher than the other.

Ager, Myers, Kerr, Myles and Green (2001), in their study looking at social integration after resettlement (n=76), report inter-rater reliability for a sample of 15 participants of 0.96, with subsection scores ranging from 0.93 to 0.97.

Ager (1988) states that Look (1987) found “highly significant” inter-correlations between total LEC score and every subsection score. Wheeler, Clare and Holland (2013), report a Cronbach’s alpha of 0.721 in their study looking at offending by people with ID (n=46) in community settings. The LEC achieved a score of 1/2 for internal consistency, due to a lack of factor analysis, and a score of 2/2 for test-retest and inter-rater reliability as all reported coefficients reached the standard of $r=0.7$.

Validity

In terms of face validity, the LEC contains 30% community participation items (see Table 2. For an overview of face validity

Table 2: Number and percentage of community participation items

Instrument	Total (N)	CP items	Non-CP items	Unclear items
LEC	50	15 (30.0 %)	30 (60.0%)	5 (10.0%)
ICI	15	15 (100%)	0	0
GCPLA	53	44 (83.0%)	9 (17.0%)	0
LCQ (Community Access subscale)	22	20 (90.91%)	1 (4.55%)	1 (4.55%)
CPI	18	18 (100)	0	0
TLAB (Activity Checklist)	132	80 (60.6%)	52 (39.4%)	0
LAI (Leisure Activity Participation Index)	53	37 (69.8)	16 (30.2)	0
CIS	12	10 (83.3)	1 (8.3%)	1 (8.3%)
UCFS	18	18 (100%)	0	0
6MIS	18	17 (94.4%)	0	1 (5.6%)

In terms of content validity, the LEC covered 7/9 ICF domains (see Table 2 for a breakdown of each measure's ICF coverage).

Table 3: An overview of the ICF domain coverage of each measure

ICF Domains of Community Participation	LEC	ICI	GCPLA	LCQ	TLAB	CPI	LAI	CIS	UCFS	6MIS
Assisting others (d660)	-	-	-	-	*	-	*	*	-	-
Particular interpersonal relationships (d730-779)	*	*	*	*	*	-	*	*	-	-
Education (d810-d839)	-	-	*	*	*	*	*	-	-	*
Work and employment (d840-d859)	*	-	-	*	-	-	-	-	-	-
Economic life (d860-d879)	*	*	*	*	-	*	*	*	*	*
Community life (d910)	*	*	*	-	*	-	-	-	-	*
Recreation and Leisure (d920)	*	*	*	*	*	*	*	*	*	*
Religion and spirituality (d930)	*	*	*	*	*	*	*	*	*	*
Political life and citizenship (d950)	*	-	-	-	-	-	-	-	-	-
Other	-	*	*	*	*	*	-	-	*	*

Ager, Myers, Kerr, Myles and Green (2001) reported a correlation between the Index of Community Involvement (Raynes, Pratt and Roses, 1979) and the LEC of 0.78 pre-move and 0.72 post-move. Ager (1988) additionally reported correlations found by Look (1987), however these do not reach the threshold of 0.5. A significant correlation was reported by Baker (2000) between the LEC category of ‘Leisure’ and the GCPLA category of ‘Leisure, sport and recreation’ (0.74), and between the LEC category of ‘Opportunities’ and the GCPLA category ‘Facilities/Amenities’ (0.55).

With 30% community participation items, the LEC scored 0/2 for face validity as the threshold of 60% was not met. For content validity the LEC scored 1/2 as 2/9 ICF domains were not covered and neither experts nor people with ID were consulted. The LEC scored 2/2 for convergent/discriminant validity as three correlations over the threshold of 0.5 were reported.

Interpretability

A general population sample was obtained (Ager et al., 1988; n= 410). Data from a group of undergraduate students (n = 227) was also presented. It is clear from the percentile ranks provided for the general population sample that floor and ceiling effects are not evident, however it is uncertain whether this would be the case with an ID sample. We are given no further demographic information about the two sample groups.

Ager, Myers, Kerr, Myles and Green (2001) report mean scores and standard deviations for all five LEC domains as well as total score. LEC scores were significantly higher following a move from an institution to the community.

Ager (1988) presents a number of means and standard deviations reported for various subgroups in other studies (many of which have small sample sizes). Comparisons between subgroups cannot be made due to the fact that the data is aggregated.

The LEC achieved a score of 1/2 (make changes to tables and conclusion) for the criterion of floor and ceiling effects due to uncertainty around the generalisability to

an ID population. For the criterion of interpretability the LEC scored 2/2 as comparison data exists with both non-ID and ID populations.

Summary and Evaluation

The LEC received an overall quality rating of 9/14 (see table 4. for an overview of quality ratings). It has reliability, validity and normative data (with the inclusion of percentile ranks), although the majority of comparison data is with a non-ID population. Despite being both an informant-report and a self-report measure, we are not advised as to which method was used for each psychometric test. The LEC is a broad based quality of life measure, with only 30% of items relating to community participation. Although the ‘Leisure’ subscale contains only community participation items, it does not contain all of the community participation items; these are embedded within the questionnaire along with many items pertaining to subjective experience. Analysis of community participation using the LEC is therefore difficult.

Table 4: An overview of *each measure’s quality ratings*

Measure	Face validity	Content validity	Factor Structure	Internal consistency	Test-retest/ Inter-rater Reliability	Convergent Validity	Floor/ ceiling effects	Interpretability	Total
LEC	0	1	0	1	2	2	1	2	9
ICI	2	1	0	0	2	1	0	2	6
GCPLA	2	1	0	1	2	2	2	2	12
LCQ	2	1	0	0	1	0	0	2	6
CIS	2	1	0	1	0	2	0	2	8
TLAB	1	1	0	0	1	0	0	2	5
LAI	1	1	0	0	1	1	0	1	5
CPI	2	1	0	0	0	0	0	1	4
UCFS	2	0	0	1	0	0	0	2	5
6 MIS	2	1	0	0	1	0	0	0	2

Rating: 0=criterion not met/insufficient data to rate criterion; 1=criterion partially met; 2=criterion fully

met

Index of Community Involvement (ICI; Raynes, Pratt & Roses, 1979)

Description

- Designed for use in the USA and later modified for use in the UK (Raynes, & Sumpton, 1986)
- Informant-report
- Yes/No checklist of 14 activities done in the past month. Also holiday in the past year
- Five published papers were found reporting novel psychometrics for the ICI.

Reliability

In terms of internal consistency, Raynes and Sumpton (1986) reported Cronbach's alphas of 0.85 (group) and 0.77 (individual) obtained with a sample (n=145) with ID. Beadle-Brown, Hutchinson and Whelton (2012; n=33) reported a Cronbach's alpha of 0.59 at baseline and 0.69 at follow-up. Chou et al. (2011), with a Taiwanese sample (n=49), reported a Cronbach's alpha of 0.62.

In ID samples, the ICI has demonstrated relatively good levels of inter-rater reliability of between 95-96% (Raynes & Sumpton, 1986; Raynes, 1988) and correlations of 1.00 pre-move and 0.97 post-move (Ager, Myers, Kerr, Myles & Green, 2001). Higgins and Mansell (2009) reported good test-retest reliability (0.8).

Felce et al. (1998) expanded the ICI to include additional social activities and an assessment of frequency. Perry and Felce (2005) reported that inter-rater agreement across items averaged 71% but was 93% when only occurrence (not frequency) was measured.

The ICI scored 2/2 for test-retest/ inter-rater reliability as the majority of correlations reported met the standard of 0.7. The ICI scored 0/2 for internal consistency because no factor analysis was conducted and the majority of Cronbach's alphas reported were below the standard of 0.7.

Validity

For face validity the ICI scored 2/2 as it contains 100% community participation items. For content validity the ICI scored 1/2 as 5/9 ICF domains were covered. Relevant experts and people with ID were not consulted.

Ager, Myers, Kerr, Myles and Green (2001; n=76), reported a correlation between the ICI and the LEC of 0.78 pre-move and 0.72 post-move. Perry and Felce (2005), with the modified ICI, found that range and frequency scores were significantly correlated with resident engagement in social activity as measured by systematic observation (Jones et al., 1999; $r = 0.16$ and 0.20). However, these correlations do not reach the required level of 0.5. Raynes and Sumpton (1986) reported that regression analysis found significant negative effects of Behavior Problems Inventory scores (Rojahn et al., 1989), age and IQ on ICI scores. Unfortunately correlation coefficients were not reported. The ICI subsequently scored 1/2 for convergent/discriminant validity.

Interpretability

Raynes and Sumpton (1986) reported mean percentage scores and standard deviations derived from various different sub samples from a study of 448 people with ID. They reported mean percentage scores and standard deviations according to level of IQ (n=148) and type of residence (voluntary home, hospital or local authority hostel;

n=175). This data was collected in the 1980s when the majority of participants were living in 'hospitals'. It is of limited use as reference data today and can only be accessed by contacting the British Library.

Ager, Myers, Kerr, Myles and Green (2001) reported mean score and standard deviation divided into pre and post resettlement (n=58). The ICI scored 2/2 for interpretability as mean scores and standard deviations from ID samples are available (although the more recent sample is relatively small) and subgroup comparisons are available, although the majority of these were reported in 1986.

Summary and Evaluation

The ICI received a quality rating of 5/14. With 100% community participation items and 5/9 domains of the ICF covered, the ICI is quick to use and has good face validity, however no factor analysis was conducted and the majority of Cronbach's alphas reported were below the standard of 0.7. In terms of validity, the correlations with relevant constructs did not produce acceptable coefficients in enough cases to satisfy the quality criterion.

Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000)

Description

- Modified version of Seager's (1987) structured interview.
- Structured interview or by-proxy questionnaire.

- 49 items in six categories: Services, Public transport, Indoor leisure, Leisure, Sport and recreation, Social and Facilities/Amenities.
- Respondent is asked about frequency (never, very occasionally, 3 monthly, monthly, weekly or daily) and level of support (supervised, with carers, unaccompanied, with a peer group).
- Scoring includes a Range score (sum of regular activities), a Busy score (sum of very frequent activities), four Independence scores (sums of activities requiring levels of support), a Total score and Total Community and Total Leisure scores.
- Two further papers were found reporting novel psychometrics for the GCPLA.

Reliability

Baker (2000) examined the inter-rater reliability of the by-proxy version with participants with severe or profound ID (n=12). The correlation coefficients were largely acceptable, ranging from 0.62 (Activities Accompanied) to 0.84 (Very Frequent Activity). Test-retest correlations using the structured interview format (n=9) were largely acceptable, ranging from 0.65 (Very frequent activities) to 0.97 (Activities alone). For the by-proxy format (n=12) the majority of correlations were acceptable, although Activities alone and Activities supervised achieved non-significant coefficients of 0.46 and 0.47 respectively. Test-retest reliability was further examined by Abraham, Gregory, Wolf and Pemberton (2002) with an ID sample (n=10). Correlation coefficients were good, ranging from 0.69 (Activities accompanied) to 0.97 (Activities alone).

Baker (2000) examined the internal consistency of the GCPLA (n=109): Scores relating to frequency produced a Cronbach's alpha of 0.93, while scores relating to

level of support produced a Cronbach's alpha of 0.82. The GCPLA scored 1/2 for internal consistency as factor analysis was not performed, and 2/2 for test-retest and inter-rater reliability as the majority of scores reached the standard of 0.7.

Validity

The GCPLA comprises 83% community participation items and 6/9 ICF domains are covered. Ten clinical psychologists working in the field rated out of five (1='not at all', 5='extremely'), the relevance of the activities to the sub-categories, and the sub-categories to the concept of community participation and leisure (Baker, 2000). The items within the subcategories were rated at between 4.2 and 4.5/5 and the relevance of the subcategories to the overall concept was rated as 4/5.

Baker (2000) reported that GCPLA scores (by-proxy form; n=11) correlated with a three-week diary as well as the LEC (Ager, 1998). Baker reported three significant correlations with diaries: 'Indoor leisure' (0.65), 'Facilities/Amenities' (0.73) and 'Total score' (0.68), with all subcategories achieving at least modest correlations. Significant correlations were found between the LEC category of 'Leisure' and the GCPLA category of 'Leisure, sport and recreation' (0.74), and the LEC category of 'Opportunities' and the GCPLA category 'Facilities/Amenities' (0.55).

Baker (2000) reported a low but significant correlation (0.33) between the by-proxy GCPLA and Adaptive Behaviour Scale (Part 1) (ABS; Nihira et al., 1974) scores. A non-significant negative correlation was also found between the by proxy GCPLA and the Behaviour Problem's Inventory (Rojahn et al., 1989) scores.

With a sample with severe-profound ID (resettlement $n=28$ and comparison $n=34$), Baker (2007) reported that the ABS Part 1 (Nihira et al., 1974), the Community Goal Rating Scale (developed by Baker for this study), and place of residence were all significantly correlated with GCPLA range scores. The values of the correlations were not reported.

The GCPLA scored 2/2 for face validity and 1/2 for content validity (experts, but not service users were consulted and 3/9 ICF domains are not covered), as well as 2/2 for convergent/discriminant validity as more than three quarters of results were in line with expectations and more than two correlations reached the standard of 0.50.

Interpretability

Baker (2000) provided normative data (using Range scores) from an ID sample ($n=109$), including percentiles that demonstrate floor and ceiling effects were not evident. Additionally, mean scores and standard deviations were reported for a group of 38 service users and a (non matched) comparison group of 41 staff. Mean scores were presented for each individual item. T-tests indicated that service users had a significantly smaller range of activities and significantly fewer activities were completed alone or with peers. Baker (2007) reported that GCPLA range scores were significantly higher in a resettled group than in an institutional-residence group.

Baker reported that gender and place of residence did not significantly affect GCPLA scores. The GCPLA scored 2/2 for interpretability as mean scores and standard deviations are reported from an intellectually disabled sample as well as a non-intellectually disabled comparison group. Baker (2000, 2007) reported on the level of

ID of the various sub-samples, however a detailed breakdown of demographics was not given.

Summary and Evaluation

With normative data (including percentile ranks), acceptable reliability and validity, and a flexible scoring system, the GCPLA received a quality rating of 12/16. It has not undergone factor analysis, the ICF domain coverage is not complete and demographic information is lacking for psychometric data.

Life Circumstances Questionnaire (LCQ; Ashman, Hulme & Suttie, 1990; Ashman & Suttie, 1996)

(‘Community Access’ subscale)

Description

- By proxy, semi-structured interview taking one hour
- Nine sections, including a ‘Community Access’ section comprised of 20 activities
- Frequency scores: never (0), monthly (1), fortnightly (2), once or twice a week (3) and every day (4). Also one question about the frequency of holidays and who accompanies the individual on holidays
- Three papers were found reporting psychometrics for the LCQ
- All data found regarding the LCQ came from the closure of one Australian institution, limiting generalisability of the findings

Reliability

Young, Ashman, Sigafoos and Grevell (2001) reported overall inter-rater reliability of 0.9. Young and Ashman (2004a; 2004b, n=104) reported inter-rater reliability of 0.88, with averages for separate domains ranging from 0.52 (social/emotional wellbeing) to 0.97 (material wellbeing). Young (2006) reported inter rater reliability of 0.95 overall and 0.95 for Community Access. The LCQ scored 1/2 for reliability, as test-retest reliability was not reported. A score of 0/2 was given for internal consistency as neither factor analysis nor Cronbach's alpha was calculated.

Validity

The Community Access subscale of the LCQ comprises 90.91% community participation items and 6/9 ICF domains are covered. The original LCQ was developed in consultation with five experts. The modified version (Ashman & Suttie, 1996) was developed in consultation with key policy makers and ID service providers. The LCQ scored 2/2 for face validity, 1/2 for content validity and 0/2 for convergent/discriminant validity as no correlations were provided.

Interpretability

Young and Ashman (2004a) presented mean scores and standard deviations (n=104) taken periodically throughout a two-year study with a mild, moderate and severe ID sample. They reported a significant positive linear increase in LCQ scores, and specifically for the Community Access domain, after deinstitutionalisation.

Young (2006) presented mean scores and standard deviations for participants moving to 'cluster-centers' or the community. Significant differences are reported for total LCQ mean scores and all domain scores at follow-up for the cluster-centre and

community dwelling individuals compared to scores in the institution. The mean scores increased by a significant amount more for the participants resettled to the community.

Summary and Evaluation

The Community Access subscale of the LCQ received a quality rating of 6/16. It has strong face validity and ICF coverage is 6/9. The LCQ is lacking test-retest reliability and convergent/discriminant validity information and, again, did not undergo factor analysis.

Community Integration Scale (CIS; Heller & Factor, 1991)

Description

- Twelve possible activities with option to specify one further activity.
- Direct interview (Yes/No response) and by-proxy (No/ 1-3 times a month/ Weekly/ 2+ times a month) versions.
- Some items are specific: “Do volunteer work”
- Some items are ambiguous: “Go to movies, sports events, concerts etc”.
- Scores on the informant report version are the mean frequency rating
- Scores on the direct interview version are the sum total of ‘yes’ responses.
- Introduced at a consortium: Not possible to ascertain whether any psychometrics were produced at the time
- Three papers reporting psychometrics for the CIS were found.

Reliability

Heller, Miller and Factor (1998), with an ID sample (n=269, 70% severe to profound ID, 46% cerebral palsy, 47% epilepsy) and using the by-proxy version, reported

Cronbach's alphas of 0.80 at baseline and 0.79 at three-year follow up. Heller, Miller and Hsieh (1999), with another ID sample (n=78, 47% severe or profound, 47% 'multiple impairments', 6% severe autism) and a caregiver sample (n=146), reported Cronbach's alpha of 0.57 at time one and 0.85 at time two (4 years later). The CIS scored 1/2 for internal consistency as factor analysis was not performed but 3/4 Cronbach's alphas reported met the criterion standard of 0.7. A score of 0/2 was given for test-retest and inter-rater reliability as no data was provided.

Validity

The CIS comprises 83.3% community participation items and 5/9 ICF domains are covered. Scores of 2/2 for face validity and 1/2 for content validity were given. Heller, Miller and Factor (1998) reported significant correlations with adaptive behaviour (measured by the ICAP, Bruininks et al., 1986; time 1 = 0.51, time 2 = 0.54) and type of facility (-0.64). As hypothesised by the authors, based on a range of previous research, they additionally reported a correlation (0.74) with level of involvement in policy-making (measured by the Decision Making scale within the Multiphasic Environmental Assessment, Moos & Lemke, 1984).

Heller, Miller and Hsieh (2002) additionally reported correlations between CIS mean frequency scores and adaptive behaviour of 0.56 at baseline and 0.54 at follow up. They also reported a significant positive correlation (0.58) with choice making (Choice Scale; Heller, Miller & Factor, 1999). A score of 2/2 was given for convergent/discriminant validity as more than two correlations reached the 0.5 standard.

Interpretability

Heller, Miller and Factor (1998; n = 269) and Heller, Miller and Hsieh (1999; n=78 ID, 146 caregivers) reported means and standard deviations for their samples. Detailed demographic information is provided, although the statement ‘multiple impairments’ (47% of Heller, Miller & Hsieh’s sample) is not explained. Heller, Miller and Hsieh (2002) additionally provide means and standard deviations for ‘movers’ and ‘non-movers’ at baseline and eight-year follow up for a mixed ID sample (n= 186, 72%, severe to profound), with movers achieving significantly higher CIS scores. It was not possible to ascertain whether floor or ceiling effects were an issue. The CIS scored 2/2 for interpretability.

Summary and Evaluation

The CIS received a quality rating of 8/16. The CIS has reference data (although some of the information about participants is unclear), acceptable validity and is quick and easy to use, however it lacks reliability testing and factor analysis.

Trail Leisure Assessment Battery (TLAB; Dattilo & Hoge, 1997)

(Activity Checklist)

Description

- Form A is a semi-structured interview based on a 132-item ‘Activities Checklist’ split into nine pictograms.
- Individuals are asked whether they have ever participated in an activity (yes=2/no=0), whether they participate now (yes/no) and whether they do so ‘a lot’ (2 points) or ‘*a little*’ (1 point).

- Form B is by-proxy and asks the frequency with which individuals have done each activity on a five-point scale (never (0) – daily (5)).
- Scores are the sum of the number of points awarded.
- Leisure behaviours, constraints and barriers to leisure can also be measured.
- Form A reportedly takes about an hour and form B about 15-20 minutes.

Reliability

Dattilo, Hoge and Malley (1996) reported test-retest reliability ($n=20$). For past activity patterns correlations ranged from 0.65 (Sports and Exercise) to 0.87 (Home-Based Creativity). For current activity patterns, overall test-retest reliability was high (0.90) however 2/9 categories did not achieve significant correlations. Dattilo et al. advised general caution in interpreting the data as they observed a strong tendency for responders to answer 'Yes' to questions.

The authors reported that inter-rater reliability was examined by comparing the responses of people with ID (Form A) and their carers (Form B). This was not a true measure of inter-rater reliability, as Form B should have been administered by two independent raters. Low but significant correlations were reported for overall past and current Recreation activity (0.21, 0.39 respectively). Significant correlations were reported for all categories for current activities but only for 5/9 categories for past participation.

Dattilo, Hoge and Malley (1996) highlighted that the absence of significant correlations in both test-retest and inter-rater reliability for the Education and Outdoor Recreation domains of the Activity Checklist raised concern about these sections. The

TLAB scored 1/2 for test-retest and inter-rater reliability as only the test-retest reliabilities reached the criterion standard of 0.7 and inter-rater reliability was not conducted appropriately.

Validity

With 60.6% community participation items The TLAB scored 1/2 for face validity. A score of 1/2 was given for content validity as 6/9 ICF domains were covered.

Interpretability

Hoge and Dattilo (1995) report means and standard deviations for each category of the Activities checklist (but not total scores), with a matched sample with (n=100) and without (n=100) ID (67% mild). They report significantly higher scores for adults without ID in all categories for past recreation, and in 8/9 of the activity categories for current recreation. The TLAB scored 2/2 for interpretability as reference data is available for adults with and without ID, however further subgroup comparisons are lacking.

Summary and Evaluation

The TLAB received a quality rating of 5/16. Normative and reliability data are available. It is a flexible measure, with by-proxy and informant-report forms. With 132 Activity Checklist items, it seems a lengthy measure to administer. Again, factor analysis was not performed and information about convergent/discriminant validity is lacking.

Leisure Assessment Inventory (LAI; Hawkins, 1991; Hawkins, Ardovino, Rogers, Foose & Olsen, 2002)

(Leisure Activity Participation Index)

Description

- The Leisure Activity Participation Index (LAPI) is divided into three domains: Social Activities, Activities at Home and Physical Activities.
- LAI also includes indices of Interest, Preference and Constraint
- Self-report structured interview
- Current participation in 53 activities.
- Scores are sums of 'yes' responses.
- Not freely available. Contact was made with the authors and publishers however it was not possible to obtain a copy of the 2002 publication. Earlier publications by the authors and subsequent publication by Badia et al. provided enough information to include the LAI in this review. It is possible that some information is missing.

Reliability

Hawkins and Freeman (1993), with a moderate ID sample (n=121), report a test-retest reliability correlation (one year apart) for the LAPI of 0.55. With another moderate ID sample (n=92) Hawkins, Ardovino and Hsieh (1998) report a test-retest reliability correlation (one year apart) for the LAPI of 0.84. The LAI scored 1/2 for test-retest reliability as only one of the two reported correlations reached the criterion standard of 0.7.

Validity

Hawkins and Freeman (1993) described how a panel of five experts reviewed the original LAI (Hawkins, 1991). Badia et al. (2012) consulted two focus groups of adults with ID when they adapted and validated the LAI for use in Spain. The LAI covers 6/9 ICF domains. A score of 1/2 was given for content validity as 3 ICF domains were not covered. The LAI contains 69.8% community participation items. This is just below the criterion threshold of 70% so a score of 1/2 was given for face validity.

In terms of convergent validity, the LAPI was positively correlated with perceived life satisfaction (0.27) as measured by the Life Satisfaction Scale – Modified (Hawkins, Eklund and Martz (1992). The index was, surprisingly, negatively correlated with social communication skills (-0.24) and community living skills (0.26) as measured by the ICAP (Bruininks, Hill, Weatherman & Woodcock, 1986). These negative correlations were proposed to be caused by either increased acquiescence of responders with lower adaptive skills or increased self-determination of responders with higher adaptive skills.

Badia et al. (2012) found LAI scores to be significantly positively correlated with three of the eight GENCAT (Verdugo, Arias, Gomez & Schalock (2009a) subscales. These were Personal Development (0.18), Self-determination (0.22) and Social Inclusion (0.20). Scores on the LAPI were not found to be significantly correlated with the Subjective Integral Quality of Life Scale (Verdugo, Arias, Gomez, & Schalock, 2009b). The LAI scored 1/2 for convergent/discriminant validity as not all of the correlations reported were in line with previous findings.

Interpretability

Hawkins, Ardovino and Hsieh (1998) reported means and standard deviations for a moderate ID sample (n=92). Badia et al. (2012) additionally presented means and standard deviations for their borderline - severe ID sample (n=237). The LAI scored 1/2 for interpretability as comparison/ sub-group data is missing.

Summary and Evaluation

The LAI received a quality rating of 5/16. The LAI contains 69.8% community participation, so was very close to the threshold of 70% for the face validity criterion. Means and standard deviations are available for both US and Spanish samples, as is convergent validity and test-retest reliability data (although the interval of one year was too long). Reliability and validity are moderate. The LAI lacks internal consistency data and subgroup comparisons to aid with interpretation. Hawkins Ardovino and Hsieh (1998) suggest that systematic acquiescence is an issue in their sample. Perhaps most importantly, in terms of likelihood of use in clinical settings in the UK, the LAI is not freely available.

Use of Community Facilities Scale (UCFS; Chou, Lin, Pu, Lee & Chang, 2008)

Description

- Developed for use in the authors' research in Taiwan.
- Self-report measure.
- Participants indicate the frequency with which they participate in 18 community activities
- Potential frequency options and timescale of activities completed are not specified

- Scores can vary from 0 to 54, with higher scores indicating greater levels of participation. No further studies were found reporting psychometric evaluation of the UCFS.
- No further papers were found reporting psychometric properties

Reliability

Chou et al. reported a Cronbach's alpha of 0.81. The UCFS scored 1/2 for internal consistency as factor analysis was not conducted.

Validity

The UCFS scored 2/2 for face validity as it contains 100% community participation items. For content validity, the ICF only covered 3/9 ICF domains so received a score of 0/2.

Higher adaptive function (as measured by the Adaptive Behaviour Scale – Taiwanese version, Shu, 2004) was reported to be a significant predictor of UCFS scores (correlation coefficient not reported). Quality of life (as measured by the QOLQ, Schalock, Hoffman & Keith, 1993) was reported not to be significantly associated with UCFS scores. The UCFS therefore scored 0/2 for convergent validity.

Interpretability

With a largely male, mild - profound ID sample (n=248), Chou et al. presented means and standard deviations according to type of living environment. Participants living in small residential homes had significantly higher UCFS scores than those living in group/community homes and institutions. The UCFS scored 2/2 for interpretability, as

sufficient reference data was available, although further sub-group comparisons were lacking.

Summary and Evaluation

The UCFS received a quality rating of 5/16. It has 100% community participation items but only 3 domains of the ICF are covered. Scoring is unclear, reliability information is lacking and only one significant association with a relevant measure is reported. Factor analysis was not conducted. Normative information is available however the Taiwanese sample may not make for useful comparisons with UK residents. Interestingly the authors used the ICI (Raynes, Pratt and Roses, 1979) in a later piece of research (Chou et al., 2011).

Community Participation Inventory (CPI; Stancliffe & Keane, 2000)

Description

- Developed for an Australian study
- By-proxy measure containing 18 community facilities
- Three scores generated: number of places used in past three months, frequency of use (sum of frequencies) and number of places used without support.
- No further papers were found reporting psychometric properties

Reliability

Stancliffe and Keane reported Cronbach's alphas for the three scores generated: Number of facilities used (0.54), frequency of use (0.21) and number of facilities used without support (0.73). A score of 0/2 was given for internal consistency as only one of these figures reached the criterion standard of 0.7.

Validity

The CPI contains 100% community participation items and received a face validity score of 2/2. With 4/9 ICF domains covered, the CPI was given 1/2 for content validity.

Interpretability

Stancliffe and Keane reported group mean scores but not standard deviations. They reported that Frequency and 'Number of places used without staff support' scores were significantly higher for participants living in semi-independent settings than those living in group homes. Due to a lack of standard deviations, the UCFS was given a score of 1/2 for interpretability.

Summary and Evaluation

The CPI received a quality rating of 4/16. Test-retest and inter-rater reliability information was missing. The majority of Cronbach's alphas were not at an acceptable level and factor analysis was not conducted. In terms of interpretability, only group means were reported and standard deviations were missing.

Six-Monthly Interview Schedule (6MIS; Lowe & de-Paiva, 1988)

Description

- Designed for use in a study.
- By-proxy structured interview
- Eighteen types of community facility (including an 'other' category)
- Number of facilities used in previous six months, and frequency of contact.
Also frequency of contact with relatives and friends.
- No further papers were found reporting psychometric evaluation

Reliability

Test-retest reliability was conducted by re-coding taped interviews after 3 months. Average agreement obtained was 97.4%: range 89.5-100%. Inter-rater agreement (2 weeks interval) obtained was 80.7%: range 68.4—89.5%.. The 6MIS received a score of 1/2 for test-retest and inter-rater reliability, as correlation coefficients were not reported.

Validity

The 6MIS contained 94.4% community participation items and was awarded a score of 2/2. For content validity, 4/9 ICF domains were covered so a score of 1/2 was awarded.

Summary and Evaluation

The 6MIS received a quality rating of 4/16. Test-retest and inter-rater reliability were the only psychometric information available and were not calculated as correlation coefficients. Mean scores and standard deviations were not reported.

Discussion

Limitations of the review

The nature of the search criteria was such that only papers reporting novel psychometric properties for each measure were included in the review. If studies did not use the name of a measure as a keyword then they were not retrieved. A few of the measures have been used widely (for example the LEC) and there may be papers not included in this review, which did not include the measure as a keyword, but contain relevant information about subgroup comparisons. It was beyond the scope of the review to examine all published data using all of the measures.

Overall, the authors feel that the quality criteria used capture the general quality of the measures. There is however, a degree of arbitrariness to the quality criteria. The criterion of coefficients greater than $r=0.7$ is perhaps generous given Kline's (2013) suggestion of $r=0.8$, with a sample larger than 100 and a test-retest interval greater than three months. Dijkers, Whiteneck and El-Jaroudi (2000) recommend that internal consistency should be eliminated or accorded limited importance as a criterion in examining social outcome measures. They argue that social outcomes should be broad and that it is unrealistic to expect strong positive correlations. They contend it might not be unreasonable to even find negative correlations: for example those who like to spend time shopping may not also spend many hours doing outdoor activities. None of the measures reviewed had undergone factor analysis, which would have helped to eliminate this issue.

Summary of tools

Results suggest that current measures of community participation for adults with ID have issues with thorough psychometric evaluation. Please see table 4.

In terms of face validity, seven of the ten measures reviewed contained more than 70% community participation items. However, no measure received the full two points for content validity due to the measures only containing between three and seven of the nine identified ICF domains of community participation. Additionally, relevant experts were rarely consulted in the process of measure development and people with ID were only consulted in one case when a researcher adapted an existing measure for use in Spain.

In terms of factor structure, all measures reviewed scored zero on this criterion, as factor analysis was never conducted. For this same reason, no measure scored the full two points for internal consistency, as inter-correlation between items in the scales could not be ensured. Only four of the ten measures reported acceptable Cronbach's alphas. In terms of test-retest and inter-rater reliability criterion, only three measures scored the full two points, with the majority of measures either not reporting or reporting unacceptable correlations.

For the criterion of convergent and discriminant validity, no measures reported discriminant validity. Only three measures produced acceptable correlations with theoretically related constructs (with at least two correlations reported and/or three quarters of the correlations reported being acceptable). Five of the measures had not reported any correlations with related constructs.

In terms of floor and ceiling effects, only one measure ruled out this issue in an ID sample. For the final criterion of interpretability, seven of the measures reported reference data, however subgroup comparisons were largely limited.

The GCPLA achieved the highest score on the quality criteria (12/16), followed by the LEC scoring 9/16. The GCPLA scored higher than the LEC due to a) stronger face validity as a measure of community participation and b) floor and ceiling effects being ruled out in an ID sample. Both measures were lacking factor analysis, the LEC was missing two domains of the ICF and the GCPLA was missing three. With the LEC lacking specificity and taking longer to administer, the GCPLA seems the current measure of choice for community participation in adults with ID.

Methodological Issues

A clear definition of the sample, in terms of demographics and level of ID was often not provided. Few of the studies used a representative sample and, in comparison studies, participants were often not matched.

It has been argued that social participation instruments are biased in favour of white, western, middle class, intellectual values (Platt, 1981; Dijkers, Whiteneck and El-Jaroudi, 2000). As socially and culturally constructed concepts, leisure experiences are impacted upon by the inequalities of society (Sasidharan, 2002). The authors of the measures reviewed here do not confront that values may have been implicitly assumed and the cultural and ethnic diversity of participants was often either not reported or not representative of British multicultural society.

As Verdonschot et al. (2009) tentatively observed, a clear theoretical or conceptual framework behind the measures was often not apparent. This was especially the case for measures that were designed for research studies. Most measures did not measure community participation as a distinct concept, but included items measuring a mixture of concepts such as functioning, domestic participation and level of support required.

Some of the same ICF domains were missing in most instruments. Political life and citizenship, assisting others, and work and employment were only measured by one, three and two instruments respectively. This lack of items referring to activities that might be considered empowering is perhaps a sign that many of these measures are outdated and hail from times when people with ID were more segregated.

Aiming for ‘normal’?

Although some reference means and standard deviations were usually available upon searching for the validation papers, the measures themselves did not include any method to determine whether participation was ‘good’ or fitted a social norm. However this links to a conceptual debate about whether there can be said to be a normative standard (e.g. Cummins & Lau, 2003). Proponents of normalisation would argue that scores should be compared to a general population norm, whilst theorists such as Cummins and Lau (2003) might argue that scores should only be compared to an ID norm.

While measuring community participation is important, it is imperative that such measures are used in an ethical and responsible way, with each individual’s own interests and wishes dictating their level of participation. The nature of scoring somebody’s community participation implicitly suggests that more is better. Cummins and Lau (2003) argue that overzealously facilitating integration for people with ID has the potential to be stressful rather than beneficial. Cummins and Lau caution that people should be in control of their own level of exposure, and not be over-encouraged by family or support staff to take part in activities in order to be more ‘normal’.

Some of the measures explicitly state that any activities organised exclusively for people with an ID must be discounted. Cummins and Lau (2003) argue that the emphasis of community participation should be on achieving a sense of connectedness. They propose that such connectedness is more likely to be achieved with other people with an ID. The authors of this review suggest that any future

measures of community participation should not differentiate between participating among people with or without ID.

Future research

Evidence suggests that ‘community presence’ and enhanced opportunities are more easily attained than, and do not necessarily lead to, community participation (Myers, Ager, Kerr & Myles, 1998). However with challenges surrounding acquiescence and recency bias in self-reporting adults with ID as well as communication difficulties to overcome in individuals with severe and profound ID, there is a need for a by-proxy measure of community participation so as to monitor lifestyles and help to facilitate any change desired. Checklist measures are easy to use and may therefore be more readily used in support services than a structured interview taking around an hour.

Refining and updating the leading measures in this review, according to the quality criteria described here, may be a good place to start in the development of a new measure. The input of more clinicians and service-users in measure design could provide a helpful voice in guiding the development of improved measures. This review has looked exclusively at measures of ‘level’ of community participation. There is also a need for measures examining experiential aspects of community participation. This will further aid the development of theory and understanding around community participation, and have practical implications for how best to conceptualise and cultivate (at individual and societal levels) true community participation in ways that support individual values and choice.

Conclusions

A systematic review of objective measures of community participation was undertaken and all identified measures were found to have significant psychometric weaknesses. Currently no thorough, psychometrically robust measure of level of community participation exists for adults with ID. Future research should focus on developing such a measure. Without adequate measures, important information about a person's quality of life may be missed, individual choice and change may not be meaningfully supported by services, and our understanding of what constitutes 'good' community participation (which may be different for different people) will likely be harder to further.

References

- Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self- esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology*,12(6), 430-443. <https://doi.org/10.1002/casp.695>
- Ager, A. (1990) *The Life Experiences Checklist*. NFER Nelson, Windsor.
- Ager, A. (1998) *The BILD Life Experiences Checklist*. British Institute of Learning Disabilities, Kidderminster.
- Ager, A., Myers, F., Kerr, P., Myles, S., & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities*,14(4), 392-400. <https://doi.org/10.1046/j.1468-3148.2001.00082.x>
- Ager A. (1988) *Life Experiences and Quality of Life in the General Population: A Study of Undergraduate Students Using the Life Experiences Checklist*. Mental Handicap Research Group Working Paper 3. University of Leicester, Leicester
- American Association on Intellectual and Developmental Disabilities (2016). Retrieved on 22/11/2016 from: <https://aaidd.org/intellectual-disability/definition#.WDSeyOLTPA>
- Ashman, A. F., Hulme, P., & Suttie, J. (1990). The life circumstances of aged people with an intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, 16(4), 335-347. <https://doi.org/10.1080/07263869000034151>

- Ashman, A. F., & Suttie, J. N. (1996). The social and community involvement of older Australians with intellectual disabilities. *Journal of Intellectual Disability Research*, 40(2), 120-129. <https://doi.org/10.1111/j.1365-2788.1996.tb00613.x>
- Badia, M., Orgaz-Baz, M. B., Verdugo, M. A., Martínez-Aguirre, M. M., Longo-Araújo-de-Melo, E., & Ullán-De-La-Fuente, A. M. (2012). Adaptation and validation of the Spanish version of the Leisure Assessment Inventory. *Intellectual and developmental disabilities*, 50(3), 233-242. <https://doi.org/10.1352/1934-9556-50.3.233>
- Baker, P. A. (2007). Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20(2), 105-109. <https://doi.org/10.1111/j.1468-3148.2006.00313.x>
- Baker, P. A. (2000). Measurement of community participation and use of leisure by service users with intellectual disabilities: The Guernsey Community Participation and Leisure Assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities*, 13(3), 169-185. <https://doi.org/10.1046/j.1468-3148.2000.00015.x>
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*. John Wiley & Sons, Chichester. <https://doi.org/10.1002/0470013435>
- Beadle- Brown, J., Hutchinson, A., & Whelton, B. (2012). Person- Centred Active Support—Increasing Choice, Promoting Independence and Reducing Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 291-307. <https://doi.org/10.1111/j.1468-3148.2011.00666.x>
- Bruininks, R. H. Hill, BK Weatherman, RF Woodcock, RW (1986). *Inventory for client and agency planning*. Allen, TX: DLM Teaching Resources. <https://doi.org/10.1037/t05609-000>

- Chang, F. H., Coster, W. J., & Helfrich, C. A. (2013). Community participation measures for people with disabilities: A systematic review of content from an international classification of functioning, disability and health perspective. *Archives of physical medicine and rehabilitation*, 94(4), 771-781. <https://doi.org/10.1016/j.apmr.2012.10.031>
- Chou, Y. C., Harman, A. D., Lin, C. J., Lee, W. P., Chang, S. C., & Lin, M. L. (2011). Outcome evaluation of active support training in Taiwan. *Research in developmental disabilities*, 32(3), 1130-1136. <https://doi.org/10.1016/j.ridd.2011.01.011>
- Chou, Y. C., Lin, L. C., Pu, C. Y., Lee, W. P., & Chang, S. C. (2008). Outcomes and costs of residential services for adults with intellectual disabilities in Taiwan: A comparative evaluation. *Journal of Applied Research in Intellectual Disabilities*, 21(2), 114-125. <https://doi.org/10.1111/j.1468-3148.2007.00373.x>
- Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of applied research in intellectual disabilities*, 16(2), 145-157. <https://doi.org/10.1046/j.1468-3148.2003.00157.x>
- Dattilo, J., & Hoge, G. (1997). *Project trail: Leisure assessment battery for people with cognitive impairments*. Georgia: University of Georgia.
- Dattilo, J., Hoge, G., & Malley, S. M. (1996). Interviewing people with mental retardation: validity and reliability strategies. *Therapeutic Recreation Journal*, 30(3), 163-178.
- Dijkers, M. P., Whiteneck, G., & El-Jaroudi, R. (2000). Measures of social outcomes in disability research. *Archives of physical medicine and rehabilitation*, 81, S63-S80. <https://doi.org/10.1053/apmr.2000.20627>
- Emerson, E. (1985). Evaluating the impact of deinstitutionalization on the lives of mentally retarded people. *American Journal of Mental Deficiency*, 90, 277-288.

- Felce, D., Lowe, K., Perry, J., Baxter, H., Jones, E., Hallam, A., & Beecham, J. (1998). Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: processes, outcomes and costs. *Journal of Intellectual Disability Research*, 42(5), 390-408. <https://doi.org/10.1046/j.1365-2788.1998.00153.x>
- Fougeyrollas, P., Noreau, L., Bergeron, H., Cloutier, R., Dion, S. A., & St-Michel, G. (1998). Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *International Journal of Rehabilitation Research*, 21(2), 127-142. <https://doi.org/10.1097/00004356-199806000-00002>
- Hawkins, B. A. (1991). An exploration of adaptive skills and leisure activity of older adults with mental retardation. *Therapeutic Recreation Journal*, 25(4), 9-28.
- Hawkins B. A., Ardovino P., Rogers N. B., Foose A. & Olsen N. (2002) *Leisure Assessment Inventory*. Idyll Arbor, Ravensdale, WA.
- Hawkins, B. A., Ardovino, P., & Hsieh, C. (1998). Validity and reliability of the Leisure Assessment Inventory. *Mental Retardation*, 36, 303-313. [https://doi.org/10.1352/0047-6765\(1998\)036<0303:varotl>2.0.co;2](https://doi.org/10.1352/0047-6765(1998)036<0303:varotl>2.0.co;2)
- Hawkins, B. A., Eklund, S. J., & Martz, B.L. (1992). *Detection of decline in aging adults with developmental disabilities: A research monograph*. Cincinnati: University of Cincinnati, Research and Training Center Consortium on Aging and Developmental Disabilities.
- Hawkins, B. A., & Freeman, P. A. (1993). Correlates of self- reported leisure among adults with mental retardation. *Leisure Sciences*, 15(2), 131-147. <https://doi.org/10.1080/01490409309513193>
- Heller, T., & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. *American Journal on Mental Retardation*, 96, 163-176.

- Heller, T., Miller, A. B., & Factor, A. (1999). Autonomy in residential facilities and community functioning of adults with mental retardation. *Mental Retardation*, 37, 449–457. [https://doi.org/10.1352/0047-6765\(1999\)037<0449:airfac>2.0.co;2](https://doi.org/10.1352/0047-6765(1999)037<0449:airfac>2.0.co;2)
- Heller, T., Miller, A. B., & Factor, A. (1998). Environmental characteristics of nursing homes and community- based settings, and the well- being of adults with intellectual disability. *Journal of Intellectual Disability Research*, 42(5), 418-428. <https://doi.org/10.1046/j.1365-2788.1998.00155.x>
- Heller, T., Miller, A. B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Family Relations*, 48(4), 419. <https://doi.org/10.2307/585250>
- Higgins, L., & Mansell, J. (2009). Quality of life in group homes and older persons' homes. *British Journal of Learning Disabilities*, 37(3), 207-212. <https://doi.org/10.1111/j.1468-3156.2009.00550.x>
- Jenaro, C., Verdugo, M. A., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W., & Schalock, R. L. (2005). Cross- cultural study of person- centred quality of life domains and indicators: a replication. *Journal of Intellectual Disability Research*, 49(10), 734-739. <https://doi.org/10.1111/j.1365-2788.2005.00742.x>
- Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., ... & Pagler, J. (1999). Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research*, 43(3), 164-178. <https://doi.org/10.1046/j.1365-2788.1999.00177.x>
- Lawton, M. P., Moss, M., Fulcomer, M., & Kleban, M. H. (1982). A research and service oriented multilevel assessment instrument. *Journal of gerontology*, 37(1), 91-99. <https://doi.org/10.1093/geronj/37.1.91>

- Look, R. J. (1987). The quality of life of mentally handicapped people: assessment of life experiences within a range of institutional and community settings. Unpublished masters dissertation. Birmingham. University of Birmingham. Department of Psychology
- Lowe, K. & de Paiva, S. (1988) The Evaluation of NIMROD, A Community-Based Service for People with Mental Handicap: Methodology Employed for the Longitudinal Study. Mental Handicap in Wales Applied Research Unit, Cardiff
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H., Coulter, D. L., Craig, E. M. P., Reeve, A., Schalock, R.L., Snell, M.E., Spitalnik, D.M., Spreat, S. and Tasse, M.J. (2002). Mental retardation: Definition, classification, and systems of supports. American Association on Mental Retardation
- Moos, R. H., & Lemke, S. (1984). Multiphasic Environmental Assessment Procedure (MEAP): Ideal and Expectations Forms. Supplementary Manual. Sheltered Care Project, Social Ecology Laboratory and Geriatric Research Education and Clinical Center, Veterans Administration and Stanford University Medical Center.
- Myers F., Ager A., Kerr P. & Myles S. (1998) Outside looking in? Studies of the community integration of people with learning disabilities. *Disability and Society* 13, 389–413. <https://doi.org/10.1080/09687599826704>
- Nihira K., Foster R., Shellhaus M. & Leland H. (1974) AAMD Adaptive Behavior Scale. American Association on Mental Deficiency, Washington, DC. https://doi.org/10.1007/springerreference_184209
- Perry, J. (2004). Interviewing people with intellectual disabilities. *The international handbook of applied research in intellectual disabilities*, 115-132. <https://doi.org/10.1002/9780470713198.ch5>

- Perry, J., & Felce, D. (2005). Correlation between subjective and objective measures of outcome in staffed community housing. *Journal of Intellectual Disability Research*, 49(4), 278-287. <https://doi.org/10.1111/j.1365-2788.2005.00652.x>
- Perry, J., & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias, and resident: proxy concordance. *Mental retardation*, 40(6), 445-456. [https://doi.org/10.1352/0047-6765\(2002\)040<0445:saoqol>2.0.co;2](https://doi.org/10.1352/0047-6765(2002)040<0445:saoqol>2.0.co;2)
- Platt, S. (1981). Social adjustment as a criterion of treatment success: just what are we measuring? *Psychiatry*; 44:95-112. <https://doi.org/10.1080/00332747.1981.11024096>
- Raynes, N. V., Pratt, M. W., & Roses, S. (1979). *Organisational structure and the care of the mentally retarded*. Croom Helm, London.
- Raynes, N. V. & Sumpton, R.C. (1986). Follow up study of 448 people who are mentally handicapped. Final report to the DHSS. Manchester, The University, Department of Social Policy.
- Raynes, N. V. (1988). *Annotated Directory of Measures of Environmental Quality*. Manchester: Manchester University.
- Rojahn J., Polster L. M., Mulick J. A. & Wisniewski J. J. (1989) Reliability of the behaviour problems inventory. *Journal of the Multihandicapped Person* 2 (4), 283±293. <https://doi.org/10.1007/bf01098170>
- Sasidharan, V. (2002). Special issue introduction: Understanding recreation and the environment within the context of culture. *Leisure Sciences*, 24(1), 1-11. <https://doi.org/10.1080/01490400252772809>
- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in

the field of intellectual disabilities. *Evaluation and program planning*, 31(2), 181-190.
<https://doi.org/10.1016/j.evalprogplan.2008.02.001>

Schalock, R. L., Hoffman, K., & Keith, K. D. (1993). *Quality of life questionnaire*. International diagnostic systems publishing Corporation.
<https://doi.org/10.1037/t10624-000>

Schalock, R. L., Verdugo, M. A., & Braddock, D. L. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, 110(4), 298-311. [https://doi.org/10.1352/0895-8017\(2005\)110\[298:csoqol\]2.0.co;2](https://doi.org/10.1352/0895-8017(2005)110[298:csoqol]2.0.co;2)

Seager M. J. (1987) *Community participation and life satisfaction amongst adults with a mental handicap who live in the community*. MPhil Thesis, University of Edinburgh, Edinburgh.

Shu, S. L. (2004) *Handbook of the Adaptive Behaviour Scale – Taiwanese Version*. Special Education Center, National Normal University, Taipei.

Stancilffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability*, 25(4), 281-305.
<https://doi.org/10.1080/13668250020019584>

Strauss, C., Taylor, B. L., Gu, J., Kuyken, W., Baer, R., Jones, F., & Cavanagh, K. (2016). What is compassion and how can we measure it? A review of definitions and measures. *Clinical psychology review*, 47, 15-27.
<https://doi.org/10.1016/j.cpr.2016.05.004>

- Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., ... & de Vet, H. C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of clinical epidemiology*, 60(1), 34-42. <https://doi.org/10.1016/j.jclinepi.2006.03.012>
- Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303-318. <https://doi.org/10.1111/j.1365-2788.2008.01144.x>
- Verdugo, M. A., Arias, B., Gomez L. E., & Schalock, R. L. (2009a). *Escala GENCAT de calidad de vida*. Barcelona, Spain: Institut Catala d'Assistència i Serveis Socials;
- Verdugo, M. A., Arias, B., Gomez L. E., & Schalock, R. L. (2009b). *Escala integral de calidad de vida*. Madrid, Spain: Editorial Ciencias de la Educacion Preescolar y Especial (CEPE)
- Wheeler, J. R., Clare, I. C., & Holland, A. J. (2013). Offending by people with intellectual disabilities in community settings: a preliminary examination of contextual factors. *Journal of Applied Research in Intellectual Disabilities*, 26(5), 370-383. <https://doi.org/10.1111/jar.12040>
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. World Health Organization.
- Young, L. (2006). Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian- matched sample. *Journal of Intellectual Disability Research*, 50(6), 419-431. <https://doi.org/10.1111/j.1365-2788.2006.00788.x>
- Young, L., & Ashman, A. F. (2004a). Deinstitutionalisation in Australia Part II: Results from a Long-Term Study. *The British Journal of Development Disabilities*, 50(98), 29-45. <https://doi.org/10.1179/096979504799103967>

Young, L., & Ashman, A. F. (2004b). Deinstitutionalization for older adults with severe mental retardation: Results from Australia. *American Journal on Mental Retardation*, 109(5), 397-412. [https://doi.org/10.1352/0895-8017\(2004\)109<397:dfoaws>2.0.co;2](https://doi.org/10.1352/0895-8017(2004)109<397:dfoaws>2.0.co;2)

Young, L., Ashman, A., Sigafos, J., & Grevell, P. (2001). Closure of the Challinor Centre II: An extended report on 95 individuals after 12 months of community living. *Journal of Intellectual and Developmental Disability*, 26(1), 51-66. <https://doi.org/10.1080/13668250020032769>

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**Section B: Development of the Guernsey Community Participation and Leisure
Assessment - Revised**

SALOMONS
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Abstract

An up to date, psychometrically robust measure of the level of community participation of adults with intellectual disabilities was not in existence, despite research identifying community participation as an important aspect of quality of life. The current research aimed to bring up to date, revise and revalidate the Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000). Adults with intellectual disabilities, carers and relevant experts were consulted in creating a 46-item GCPLA-R. The measure was then tested and the data from 153 adults with intellectual disabilities were analysed for their factor structure and psychometric properties. Factor analysis discovered a stable set of factors describing three different clusters of community participation activities. A full and a brief version of the scale were produced, each containing the three sub-scales. Both the 22-item and 46-item GCPLA-R were found to have satisfactory reliability. Scores on the GCPLA-R were related to challenging behaviour and adaptive behaviour in theoretically consistent ways, and were correlated with scores on comparable measures. The 46-item GCPLA-R was selected for publication due to its stronger face and content validity. The outcome of the analyses is discussed, along with limitations and implications for future research and clinical practice.

Introduction

Intellectual disability originates before the age of 18 and is characterized by significant limitations in intellectual functioning and adaptive behaviour, covering many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities; AAIDD, 2016).

A key consideration in relation to people with intellectual disability is the degree to which they participate in the local community. As highlighted by Verdonschot, de Witte, Reichrath, Buntinx and Curfs (2009), theoretical models such as the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), include community participation as a fundamental aspect of human functioning. Community participation is considered a 'process by which other goals are achieved' (Myers, Ager, Kerr & Myles, 1998; Emerson, 1985, p. 280). Specifically, research has shown that participation in community and leisure activities by people with intellectual disabilities encourages their inclusion in the community, improves their perception of quality of life and contributes to the acquisition of adaptive skills (e.g. Cummins & Lau, 2003). However, people with intellectual disabilities participate in their local community less than non-disabled and other disability groups (Verdonschot et al., 2009).

It is generally accepted that policies and procedures should include the facilitation of community participation in the daily lives of people with intellectual disability (Verdonschot et al., 2009). An accurate measure of community participation is therefore needed in order that services can support requirements and monitor

participation. However Verdonschot et al. reported that instruments measuring community participation among adults with intellectual disability were often ad hoc and unvalidated. Chang, Coster and Helfich (2013), in a meta-analysis of 17 community participation measures (including only four designed for adults with intellectual disability), reported that the percentage of items pertaining specifically to community participation was often low. They also highlighted that no single measure covered all nine domains of the ICF that could be classified as community participation: (1) assisting others (who do not live in the same household) (ICF code d660), (2) particular interpersonal relationships (d730-d779), (3) education (d810-d839), (4) work and employment (d840-d859), (5) economic life (d860-d879), (6) community life (d910), (7) recreation and leisure (d920), (8) religion and spirituality (d930), and (9) political life and citizenship (d950).

Community participation scales can be split into two clusters, with one cluster measuring the amount, frequency and variety of community participation, and the other cluster measuring the experience, satisfaction with and impact on wellbeing of community participation. Whilst the latter can provide insight into meaning and internal experience, the former can provide quantifiable, standardized information to detect change or compare with other settings/populations (Chang, et al., 2013). This study was driven by the need to develop an up to date, comprehensive and psychometrically robust measure of the amount, frequency and variety of community participation of people with intellectual disabilities, since no such measure currently exists (Taylor-Roberts, 2016). In particular, it focused on updating and revalidating the Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000). This measure was selected for updating over other measures because the

GCPLA had the strongest psychometric properties of measures to date (Taylor-Roberts, 2016).

The Guernsey Community Participation and Leisure Assessment

The Guernsey Community Participation and Leisure Assessment (GCPLA) is a modified version of Seager's (1987) structured interview. The GCPLA was designed to be used as either a structured interview or a by-proxy questionnaire. It contains six categories: Services, Public transport, Indoor leisure, Leisure, Sport and Recreation, Social and Facilities/Amenities. For each of the 49 items the respondent is asked about frequency (never, very occasionally, three monthly, monthly, weekly or daily) and level of support (supervised, with carers, unaccompanied, with a peer group). Scoring produces a Range score (sum of regular activities), a Busy score (sum of very frequent activities), four Independence scores (sums of activities at each level of support), a Total score and also Total Community and Total Leisure scores. Please see Appendix 2.

With Cronbach's alphas reported between 0.93 and 0.82 (Baker, 2000), the GCPLA had acceptable internal consistency. However, factor analysis was not conducted. Test-retest and inter-rater reliability was generally acceptable, with the majority of scores reaching at least 0.7 (Baker 2000). The GCPLA had good face validity and 6/9 ICF domains were covered (Chang et al., 2013; Taylor-Roberts, 2016). Ten clinical psychologists working in the field were consulted in the development of the GCPLA. However, adults with intellectual disability were not consulted. The GCPLA has acceptable convergent validity, with significant correlations reported between the GCPLA and a) a three-week diary, b) the LEC (Ager, 1998), c) the Adaptive

Behaviour Scale (Part 1) (ABS; Nihira et al., 1974), and d) place of residence (Baker, 2000; 2007). Normative were provided, along with percentiles demonstrating that floor and ceiling effects were not evident. Mean scores and standard deviations were additionally reported for a comparison group of staff. Service users were reported to have a significantly smaller range of activities and significantly fewer activities were completed alone or with peers.

Three domains of the ICF were not covered by the GCPLA (Assisting Others, Work and Employment, and Political Life and Citizenship; Taylor-Roberts, 2016; Chang et al., 2013). Additionally adults with intellectual disabilities were not consulted in its development and factor analysis was not conducted. Additionally, the GCPLA was published 16 years ago at the time of writing and contained a number of items that were outdated (e.g. watch videos).

Therefore, no up-to-date, psychometrically robust measure of level of community participation was in existence for adults with intellectual disabilities. Such a measure was needed to ensure that important information about a person's quality of life can be captured, individual choice and change can be meaningfully supported by services, and our understanding of what might constitute 'good' community participation for people with intellectual disabilities can be furthered. The intention of this study was to create just such a measure by revising and revalidating the GCPLA

Aims and Hypotheses

Aims

This study aimed to create a measure of community participation and leisure activity that could be used in a variety of contexts with a diverse range of people with intellectual disabilities. The measure would need to be designed as a by proxy measure primarily, so as to be suitable for use with individuals with moderate to profound intellectual disability. The scale would need to demonstrate sufficient reliability and validity.

The development of the Guernsey Community Participation and Leisure Assessment – Revised (GCPLA-R) would involve consultation with focus groups, before conducting exploratory analyses of a large pool of items with no predictions or limitations regarding the number or contents of factors that would emerge. Item inclusion in the initial pool would be guided by themes that emerged from the focus groups as well as the community participation domains of the International Classification of Functioning (ICF).

Specifically, it was intended to create a measure that would demonstrate a) good face and content validity through thoughtful consultation and good ICF domain coverage, b) adequate test-retest and inter-rater reliability, b) good construct validity by correlating moderately ($r \approx 0.3 - 0.7$) with a seven-day diary and an existing measure of community participation, c) a theoretically consistent relationship with measures of adaptive and challenging behaviour (higher levels of perceived challenging behaviour would be associated with lower scores on the GCPLA-R (e.g. Baker, 2000; and as

highlighted by Emerson's 1995 definition of challenging behaviour) and higher levels of adaptive functioning would correlate with higher scores on the GCPLA-R (e.g. Baker, 2000; Chou, Lin, Pu, Lee & Chang, 2008, Heller, Miller and Factor, 1998)) and d) multiple reliable factors reflecting distinct aspects of community participation.

Methods

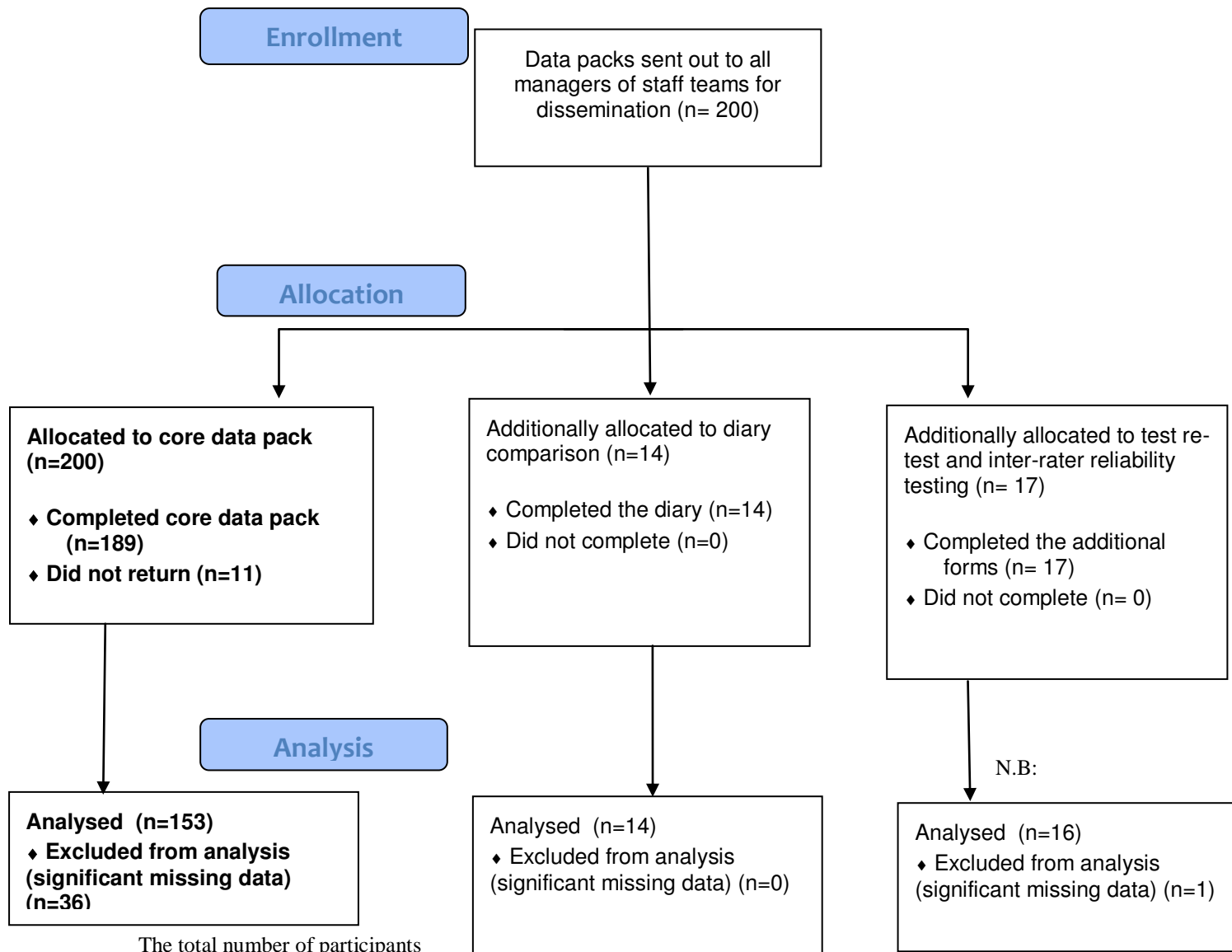
Design

Measure revision and revalidation proceeded in a series of stages. The focus group and consultation stage used qualitative methods, taking on a discovery-oriented approach. Exploratory factor analysis was conducted to ascertain a factor structure and appropriate items for inclusion in the final measure. The psychometric properties of the revised measure were evaluated using quantitative methods, including test-retest and inter-rater reliability testing.

Participants

The focus group stage included two focus groups, one for staff and carers (n=6) and one for people with intellectual disabilities (n=9). One hundred and fifty three individuals with intellectual disabilities (87 men, 66 women) with a mean age of 45.18 years (SD = 13.35, range = 18-74) comprised the final sample. See Figure 1 for a Consort diagram and Table 1 for demographic information.

Figure 1: Consort diagram



The total number of participants

was 153. All participants were allocated to the core data packs. The further allocations were additional to the core data packs. The factor analysis was conducted using the data of all 153 participants.

The large supported accommodation service from which the participants were recruited was based across three counties in the south of England and included many rural locations. The service supported individuals with intellectual disabilities ranging from moderate to profound. It was not possible to record individuals' levels of intellectual disability as this information was not readily available to support staff.

Table 1: Gender, ethnicity and age information

Variable	n (%)
Gender	
Female	66 (43.1)
Male	87 (56.9)
Self-Reported Ethnicity	
White British	147 (96.1)
White European	4 (2.6)
Mixed White/Asian	2 (1.3)
Age	
18-24	8 (5.3)
25-44	66 (43.7)
45-64	62 (41.1)
65+	15 (9.9)

After consultation with a SAGE (Salomons Advisory Group of Experts by Experience) representative, it was decided that having two separate focus groups, for a) people with intellectual disabilities and b) family members, care staff and professionals, would enable the opinions of both groups to more clearly emerge (See Appendix 3 for focus group information sheets). The family members, care staff and professionals were largely familiar with using the GCPLA and were invited

from a pool of local contacts. The focus group for people with intellectual disabilities took place at a local day service and the group consisted of service users. The day service supported a large number of service users coming from a variety of different locations in the southeast (rural, urban and suburban). This focus group was conducted in an informal manner with an open door policy.

Ethics

A University Ethics Committee granted ethical approval for this study (Appendix 4) and the British Psychological Society's (BPS) Code of Ethics and Conduct was adhered to throughout (BPS, 2009). Confidentiality was maintained through the use of anonymous ID numbers. All completed data packs were stored in a locked cabinet and data were coded and kept on a password-protected computer. In order to acquire informed consent, the information sheet (Appendix 5) was given to all participants. Staff members were asked to assess the capacity of the individual with an intellectual disability to give their own informed consent, and to either read through the information sheet (an adapted version) with them and seek their signed consent, or to fill out the consent form (Appendix 6) on their behalf (if the decision was taken that they did not have the capacity to give their informed consent). Written informed consent was obtained in all cases.

Procedure

Before constructing the GCPLA-R, focus group participants were asked how the GCPLA could be improved or updated. In the focus group involving staff and carers, participants filled out the GCPLA about their own community participation and leisure activities. The discussion was then divided into two parts; the shortcomings of

the GCPLA and ideas for improvement. The focus group was transcribed and key themes were drawn out. Please see Appendix 7.1.

In the focus group for adults with intellectual disabilities, a slide show of picture prompts (Appendix 8) was used to aid in the discussion of each activity covered by the GCPLA. Group members were asked if they did each activity or knew other people who did and if they enjoyed it. When activities did not seem relevant, participants were asked whether this was due to lack of interest or a lack of opportunity. Participants were asked if any activities were missing. The audio recording of this focus group was unfortunately not clear enough to transcribe. However the structured nature of the discussion meant that key themes were easy to draw out from written notes taken during the group.

Following the focus groups a revised GCPLA was drafted and sent to members of the focus group for staff and carers for comments. This draft was then further revised before its use during the testing stage of the project. The end result was the GCPLA-R (Appendix 10), which comprised a large item pool intended to capture community participation activities in the general population as well as in adults with intellectual disabilities. The GCPLA-R and other standardised measures were administered by sending questionnaire packs to staff. A number of staff meetings were attended by the lead investigator so as to provide further explanation and answer questions, as well as to hand out participant information sheets. Managers of each service coordinated the dispersal of questionnaire packs amongst their staff and allocated a service user to each member of staff (to ensure the GCPLA-R was not completed twice for the same individual). It was made clear that participation was voluntary. Two £50 gift vouchers

were offered in a prize draw. The lead investigator attended two services so as to facilitate inter-rater reliability testing and oversee test-retest reliability testing. Inter-rater reliability testing was conducted by asking staff to complete the core data pack and then give an additional GCPLA-R form to a colleague who also worked closely with the service user in question. Test-retest data was captured by asking the subsample of staff to complete the GCPLA-R again after at least 6 days had elapsed.

Measures

One aspect of the convergent validity testing involved comparing the GCPLA-R with a seven-day diary. For this purpose a simple diary was constructed containing all items within the GCPLA-R (see Appendix 11).

Standardised Measures

Existing measures were used to test construct validity by a) comparing the GCPLA-R with similar measures in order to test its convergent validity, and b) examining the relationship between the GCPLA-R and adaptive skills and perceived challenging behaviour, and comparing this relationship to previous findings.

The Shortened Adaptive Behaviour Scale

The Shortened Adaptive Behaviour Scale (SABS; Hatton et al., 2001) is a 24-item short form of the 73-item Adaptive Behaviour Scale Residential and Community (Part 1)(ABS-RC2; Nihira, Leland & Lambert, 1993a: 1993b). Part 1 of the longer form of the measure is “designed to evaluate coping skills considered important to personal independence and responsibility in daily living” (Nihira et al., 1993b, pp. 2-3). The SABS splits the 24 items into three factors: Factor A (personal self sufficiency),

Factor B (community self-sufficiency) and Factor C (personal-social responsibility). Hatton et al. report good internal consistency (alphas of 0.89 - 0.98), high correlation with full ABS-RC2 Part 1 equivalents ($r=0.97 - 0.99$) and high levels of agreement between predicted quartile scores and actual full ABS-RC2 Part 1 quartile scores (Kappa 0.75-0.89; percentage agreement 82%-92%).

The Aberrant Behaviour Checklist

The Aberrant Behaviour Checklist (ABC; Aman et al. 1985a) was developed to assess treatment effects in people with intellectual disabilities. Since its original publication, the ABC has been used in over 325 studies, and has been translated into more than 30 languages (Aman 2012). The 58-item questionnaire is graded on a four-point scale (0: the behaviour is not at all a problem, to 3: it is a very significant problem). Aman et al.'s (1985b) factor analysis yielded five sub-scales (irritability, lethargy, stereotyped behaviour, hyperactivity and inappropriate speech). The ABC has been reported to have sufficient psychometric properties. Aman et al. (1985b) originally reported good internal consistency for each factor (alphas of 0.86 - 0.94), acceptable inter-rater reliability for each factor (mean = .63), high test-retest reliability ($r_s = 0.96 - 0.99$) and moderate agreements between ABC subscales and relevant ABS Part 2 ('Problem Behaviors') domains ($r_s = 0.42 - 0.69$). Additionally, many researchers have reported satisfactory psychometric properties in more recent years (e.g. Aman et al. 1985b; Rojahn & Helsel 1991; Marshburn & Aman 1992; Richman et al. 2013).

The Index of Community Involvement

The Index of Community Involvement (ICI; Raynes, Pratt and Roses, 1979) is a simple informant-report Yes/No checklist of whether 14 activities have been done in the past month. The final item asks whether the person has been on holiday in the past year. Higher total scores indicate greater community participation. The ICI has good face validity and 5/9 ICF domains of community participation are covered (Taylor-Roberts, 2016). Reported Chronbach's alphas vary between 0.85 (Raynes & Sumpton, 1986) and 0.59 (Beadle-Brown, Hutchinson & Whelton, 2012). The ICI is simple to use, has been widely reported in research, and has good face validity.

Data Analysis

Initially themes from the two focus groups were examined in order to construct a draft GCPLA-R to be used in the test stage of the project.

Based on effect sizes observed by Baker (2000) with an alpha level of 0.05 and power of 0.8, the G*Power statistical power analysis program (Faul, Erdfelder, Lang & Buchner, 2007) suggested a minimum of 40 core data packs needed to be filled out, with a minimum of thirteen GCPLA-R forms filled out twice for inter-rater reliability testing and eight GCPLA-R forms filled out twice for test-retest reliability. Additionally, G*Power suggested fourteen seven-day diaries and fourteen ICIs should be completed in addition to the core data pack in order to examine construct validity. In order to conduct factor analysis, Gorsuch (1983) and Kline (1979, p. 40) recommend a sample size of at least 100 (MacCallum, Widaman, Zhang & Hong, 1999), while Hutcheson and Sofroniou (1999) recommend a minimum of 150 cases (as cited by Garson, 2008). With a final sample size of 153, it was appropriate to persevere with factor analysis as well as reliability and validity calculations.

When considering whether to use principal components analysis or exploratory factor analysis, Baglin 's (2014) advice was adhered to in that exploratory factor analysis is more theoretically aligned to the goals of exploring the dimensionality of a scale proposing to measure a latent variable. Following Field's (2013) guidance, a principal axis factoring methodology was applied to GCPLA-R data for item reduction and factor extraction. The factor structure of the scale was verified by forced factor extraction.

As the data collected were frequency data, it was felt that activities not currently participated in should not be automatically excluded from the measure simply because they may not currently be available to the individuals involved with the study. In this way, it was felt that limiting the scale to factor-loading items may only serve to perpetuate the expectation that adults with intellectual disabilities only participate in a limited range of activities. Due to this uncertainty about whether or not to exclude non-factor-loading items from the final list, all validity and reliability calculations were conducted for the 46-item GCPLA-R as well as a shorter version created by deleting non factor-loading items. The decision as to whether to include non-factor-loading items in the final scale could then be informed by the results of the reliability and validity analyses.

Cronbach's alphas were calculated for total and subscale scores in order to ascertain internal consistency. The GCPLA-R's construct validity was examined by calculating correlations with a related questionnaire and the seven-day diary. GCPLA-R test-retest and inter-rater reliabilities were computed using a sub-sample of sixteen

participants. Correlational analyses were applied to examine the relationship between GCPLA-R scores and age, gender, adaptive skills and perceived challenging behaviour. Comparisons were made between GCPLA-R scores for individuals with and without intellectual disabilities using Mann Whitney U-test analyses.

Results

The results section below has been structured according to the timeline within which analyses were undertaken. The first stage of the analysis involved drawing key themes from the focus groups. After this the 46-item GCPLA-R was analysed. Initially, missing data were examined and multiple imputations were made where appropriate. Preliminary analyses were then undertaken to determine the suitability of the data for further analyses. The factor structure of the GCPLA-R was then examined and its psychometric properties and demographic determinants were calculated.

Focus Groups

The focus group data did not lend itself well to formal thematic analysis but nevertheless important information emerged. Throughout the two focus groups three superordinate themes were identified. These were: conceptual discussion points, ease of use of the measure and specific suggestions for items that should be changed, added or deleted from the measure. See Appendix 7.1 for a detailed breakdown of the content of these three themes. See Appendix 9 for a transcription of the first focus group. Unfortunately the second focus group could not be transcribed due to poor recording quality, however thorough notes were taken during the focus group.

Development of the GCPLA-R

Following the focus groups the GCPLA-R was developed. To explore a range of possible community participation and leisure activities, a pool of 46 items was constructed by the researchers (see Appendix 10). This included many of the items in the original GCPLA (mostly with updated names and re-worded definitions) as well as a number of new items. Items were scored according to the frequency with which they were participated in (0= Never - 5= Daily or more frequently).

Missing Data

Initially the percentage of missing data was calculated for each filled-out data pack. This involved counting how many items of the GCPLAR, ABC, sABS and ICI were missing (or partially filled out) for each participant. As participants had filled out different numbers of questionnaires the percentage was calculated for each person's overall number of questionnaires filled out.

For participants with 20% or more overall missing data, data packs were examined and subsequently discarded if two or more filled-out questionnaires contained subscales with 20% or more missing data (Mazza, Enders & Ruehlman, 2015). Where only one questionnaire in a data pack contained a subscale with more than 20% missing data, individual questionnaires were excluded from further analysis. Where a questionnaire contained missing data that did not amount to 20% of a subscale, pro-rating was used. Missing data within the GCPLA-R was simply recorded as a blank and pro-rating was not used. See Figure 1 for a Consort diagram.

Pro-rating methodology

The ICI contains 15 items, which are all answered yes/no (1/0 points). Following the guidance of Taylor and Amir (1994) regarding pro-rating categorical items, an intermediate value of 0.5 was assigned where data were missing. For the ABC and the sABS, mean scores were calculated and imputed per participant and per subscale (Mazza et al., 2015).

GCPLA-R: Preliminary Analyses

Before conducting factor analysis on the GCPLA-R, Bartlett's test of sphericity, the Kaiser-Meyer-Olkin (KMO) measure and values in the anti-image correlation matrix were inspected to determine sampling adequacy (Dzuiban & Shirkey, 1974; Kaiser & Rice, 1974).

The KMO measure verified the sampling adequacy for the analysis, $KMO = 0.63$ and Bartlett's test was significant ($p < .001$) indicating an adequate sample for factor analysis (Field, 2013). A minority of anti-imaging values ($n=9$) were not greater than the acceptable limit of 0.5 (Field, 2013). Following Field's guidance, these items (attend doctor, attend dentist, attend hospital, play solitary games, watch TV, watch sport live, creative activities, gardening and spend time with family) were excluded prior to running the factor analysis.

The response distribution for each of the 46 items was then checked for skewness and kurtosis (Kendall & Stuart, 1958) and no items were excluded for this reason. In terms of communalities, all items had communalities greater than 0.5, except for 'spend time with family'. This confirmed that this item should be excluded prior to

factor analysis (Field, 2013). After excluding the nine items, the preliminary analyses were conducted for a second time, resulting in an acceptable KMO value of 0.71 (described as 'middling' by Hutcheson and Sofroniou, 1999).

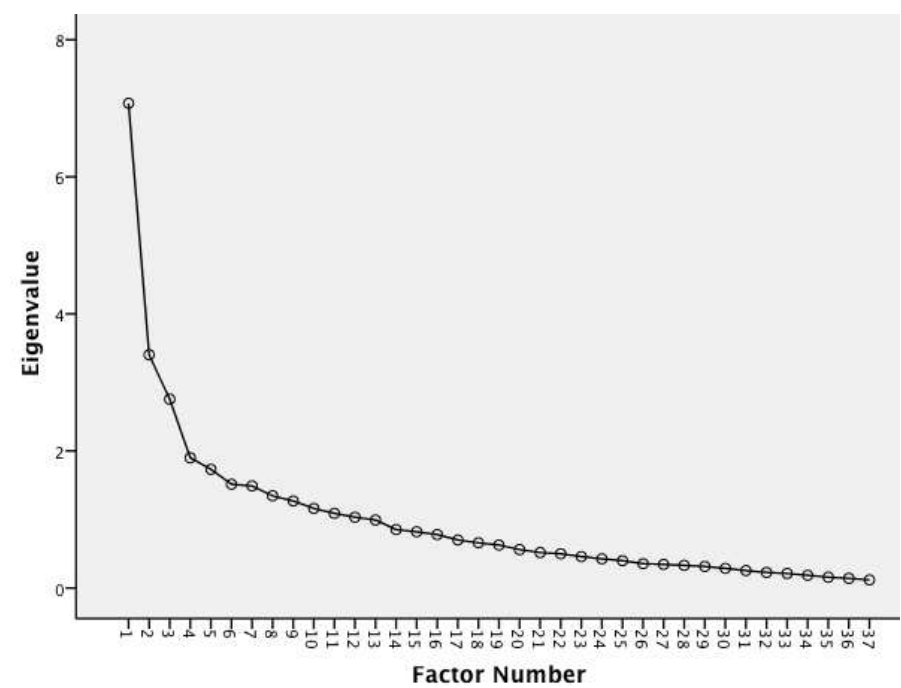
Exploratory Factor Analysis

Following Field (2013), the associations among the remaining 37 GCPLA-R items were examined via principal axis factoring using an oblique (Promax) rotation with Kaiser normalisation. Oblique rotation was selected based on Baglin's (2014) advice that oblique rotation methods should be chosen by default when using exploratory factor analysis to develop assessment measures with ordinal data, as most factors in a multidimensional scale will share some degree of relationship.

An initial analysis was run to obtain eigenvalues for each factor in the data. The initial solution produced 12 factors, which together explained 69.65% of the variance (Appendix 7.2). Examination of the Scree Plot (Figure 2) showed inflexions that justified retaining four factors. Guadagnoli and Velicer (1988) advocate that reliable factors should contain four or more loadings and Stevens (1992) advises a cut-off of 0.4 for an item to be accepted into a factor. A three-factor solution was therefore indicated as factors 4-12 contained fewer than four items with loadings above 0.4. Four factors accounted for 40.1% of the variance whereas three factors account for 35.76%.

Items with a loading below 0.4 were excluded, along with items with loadings greater than 0.4 onto more than one factor. This resulted in a final scale with 22 items (7 items in factor 1, 6 items in factor 2 and 9 items in factor 3).

Figure 2: Scree plot showing inflexions justifying the retention of four factors



Forced Factor Extraction

With the understanding that three factors were indicated, the analysis was run again but this time forced to find three factors. Table 4 provides the pattern matrix of the final 22 item GCPLA-R showing loadings of items onto each factor.

Table 4: Pattern matrix of the 22-item GCPLA-R

	Factor		
	1	2	3
Supermarket	.790		
High street store	.789		
Shop/ post office	.728		
Walk	.670		
Restaurant/ cafe	.641		
Public transport	.544		
Pub	.490		
Bank		.743	
Internet		.726	
Social network		.642	
Work		.631	
Help others		.474	
Citizenship/ political		.378	
Sport (participate)			.583
Participate drama/ music			.540
Swimming			.535
Cinema			.524
Attend live arts			.475
Exercise class			.458
Games with others			.442
Education			.428
Holiday daytrip			.332

Extraction Method: Principal Axis Factoring.

Rotation Method: Promax with Kaiser Normalisation

Rotation converged in 5 iterations.

This factor structure was verified using a direct oblimin oblique rotation with Kaiser normalisation. This produced the same three-factor solution, increasing the credibility of the scale's factor structure.

Factor Structure

The three factors found to comprise the GCPLA-R were as follows:

Factor 1 explained the largest proportion of the variance of the total scale (22.1%) and was labeled 'Accessing community facilities'.

Factor 2 explained 12.5% of the variance and was labeled 'Activities of empowerment'.

Factor 3 explained 11.11% of the variance and was labeled 'Enrichment'.

Reliability and Validity Analysis

Due to the reasons discussed in the Methods section above, all reliability and validity analyses were calculated for the scores on each of the three subscales, as well as for the 22-item total (all items within the three subscales) and the 46-item total (all items suggested by the focus groups and included in the draft GCPLA-R).

For the purpose of comparing scores both within and between groups, individual GCPLA-R mean scores were calculated. All GCPLA-R scores reported below are

based on individual mean scores. For all reported scores (the 22-item total, the 46-item total and each of the three subscale totals), item scores were summed and then mean scores were calculated. Where more than 20% of GCPLA-R data were missing, either for a total score or a subscale score, a mean was not calculated and the score was excluded from the analysis.

Internal Consistency

Each of the three subscales demonstrated good internal consistency (Chronbach's $\alpha > 0.70$; Table 5), within the region indicated by Kline (1999). No items within the subscales were identified as problematic (causing the reliability to increase if removed from the scale).

Table 5: Internal consistency

Scale	Chronbach's alpha
Accessing Community Facilities	.82
Activities of Empowerment	.76
Enrichment	.71
22-item total	.80
46-item total	.84

The internal consistency for the total score of all 22 items that contributed to the subscales was high (Chronbach's $\alpha = 0.80$). One item (play games with others) was identified as having a low corrected item correlation (0.12) and creating a higher overall reliability ($\alpha = 0.81$) if excluded from the scale. As this item was not identified as problematic within the initial subscale analysis it was decided not to exclude this item from the scale at this stage.

When all items from the original draft GCPLA-R (n=46) were included in the analysis the Cronbach's alpha was also high (0.84). This should be interpreted with some caution as Field (2013) points out that alpha values increase as the number of items in a scale increase. Additionally, four items were identified as having an extremely low corrected item correlation (<0.138) and creating a higher overall reliability (Cronbach's alpha = >0.84) if excluded from the scale. These items were; attend the hospital, attend the doctor, spend time with family and play solitary games. These were all items that had not been included in any of the three subscales by the exploratory factor analysis.

Internal Correlations

Correlations between GCPLA-R subscales were calculated to provide information about interrelationships between the factors. Bivariate Spearman's correlations (two-tailed) were calculated for all three subscales of the GCPLA-R and only the correlation between Accessing Community Facilities and Activities of Empowerment was found to be significant ($r_s = 0.25$, 95% CI [0.10, 0.40], $p < 0.001$) for two-tailed hypotheses. Following Cohen's (1988) guidelines, all subscale scores were appropriately correlated with 46-item total scores and 22-item total scores ($r_s > 0.5$, $p < 0.001$). See Appendix 7.3 for a breakdown of internal correlations.

Test-Retest Reliability

Test-retest reliability was based on a subsample of 16 participants and was calculated after an interval of between six days and six weeks. Bivariate Spearman's correlations

(two-tailed) were calculated for the scores at test and re-test. The correlation coefficients for the 22-item subscale total, the 46-item total and the three subscales were all high and significant. See Table 7.

Table 7: Test re-test reliability correlation coefficients

Scale	Spearman's rho	95% Confidence Interval
Accessing Community Facilities	.80 **	.51, .96
Activities of Empowerment	.93 **	.73, .99
Enrichment	.96 **	.85, .99
22-Item Subscale Total	.80 **	.34, .98
46-Item Total	.79 **	.37, .98

**Correlation is significant at the 0.01 level (1-tailed)

*Correlation is significant at the 0.05 level (1-tailed)

Inter-rater Reliability

Inter-rater reliability was based on a subsample of 16 participants. Bivariate Spearman's correlations (two-tailed) were again calculated. The correlation coefficients for the scores of the three different subscales and the 46-item total were all significant. The correlation coefficient for the scores of the 22-item total approached significance ($p = 0.082$) and fell into the category of 'moderate' as described by Fleiss (1981). See Table 8.

Table 8: Inter-rater reliability correlation coefficients

Scale	Spearman's rho	95% Confidence Interval
Accessing Community Facilities	.55 *	.07, .85
Activities of Empowerment	.86 **	.55, .97
Enrichment	.61 *	.06, .91
22-Item Total	.45	-.13, .82
46-Item Total	.55 *	.03, .83
**Correlation is significant at the 0.01 level (1-tailed)		
*Correlation is significant at the 0.05 level (1-tailed)		

Construct Validity

To assess the convergent validity of the GCPLA-R, correlations were examined between scores on the GCPLA-R and a) the ICI and b) the seven-day diary. In order to ascertain whether the GCPLA-R related to the constructs of challenging behaviour and adaptive behaviour in theoretically consistent ways, correlations with these measures were also examined. Additionally, comparisons are reported below between the GCPLA-R scores of people with and without intellectual disability.

ICI scores

Following bivariate Spearman's correlational analysis (two tailed), significant positive correlations were found between the ICI and the 46-item total scores ($r_s = 0.69$, 95% CI [.54, .79], $p < 0.001$), the 22-item total score items scores ($r_s = 0.68$, 95% CI [.53, .80], $p < 0.001$), Accessing Community Facilities scores ($r_s = 0.49$, 95% CI [.28, .65], $p < 0.001$), Activities of Empowerment scores ($r_s = 0.35$ 95% CI [.12, .54], $p < 0.001$) and Enrichment scores ($r_s = 0.54$, 95% CI [.36, .68], $p < 0.001$).

Seven-day diaries

The delay between filling out the GCPLA-R and beginning the seven-day diary was between 31 and 70 days (mean= 49.5 days). Correlations between the GCPLA-R and the diary entries were computed. Bivariate Spearman's correlational analyses (two-tailed) were again computed to ascertain the associations between GCPLA-R mean scores and diary entries. Significant positive correlations were found between diary entries and the 46-item total scores ($r_s = 0.77$, 95% CI [.38, .94], $p < 0.001$), the 22-item total scores ($r_s = 0.83$, 95% CI [.38, .99], $p < 0.001$), Activities of Empowerment ($r_s = 0.66$, 95% CI [.16, .94], $p < 0.05$) and Enrichment ($r_s = 0.53$, 95% CI [-.03, .92], $p < 0.05$). A positive correlation was also found between the diary entries and Accessing Community Facilities, which approached significance ($r_s = 0.52$, 95% CI [-.12, .92], $p = 0.058$) and fell into Feliss' (1981) 'moderate' category.

Adaptive skills

Bivariate Spearman's correlational analysis (two-tailed) found that there were significant positive correlations between service users' scores on the sABS and the 22-item GCPLA-R as well as the 46-item GCPLA-R. The Accessing Community Facilities and Enrichment subscales of the GCPLA-R were found to be significantly positively correlated with the total sABS score. Additionally, the Accessing Community Facilities subscale was significantly positively correlated with the sABS Personal and Community Self Sufficiency subscales, and the Empowerment subscale was significantly positively correlated with all three sABS subscales (Appendix 7.4).

The GCPLA-R subscale of Enrichment was found not to be significantly associated with adaptive skills, however a negative correlation with the sABS subscale Personal

Self-Sufficiency approached significance using the two-tailed test, suggesting that individuals who were considered more self-sufficient scored lower on Enrichment.

‘Challenging’ behaviour

Bivariate Spearman’s correlational analysis (two-tailed) found that there were significant negative correlations between service users’ scores on the 22-item total as well as the 46-item total and the ABC subscales of Irritability, Lethargy and Stereotypy. Correlations with Hyperactivity approached significance. (See Table 10).

Table 10: Correlations between GCPLA-R and ABC scores

	ABC Irritability	ABC Lethargy	ABC Stereotypy	ABC Hyperactivity	ABC Inappropriate speech
46-Item Total	-.173*	-.305**	-.183*	-.150	-.097
22-Item Total	-.176*	-.311**	-.192*	-.141	-.045
Accessing Community Facilities	-.040	-.083	-.091	-.033	-.002
Activities of Empowerment	-.123	-.180*	-.232**	-.138	.149
Enrichment	-.146	-.229**	.006	-.090	-.117

** Correlation is significant at the 0.01 level (2-tailed).

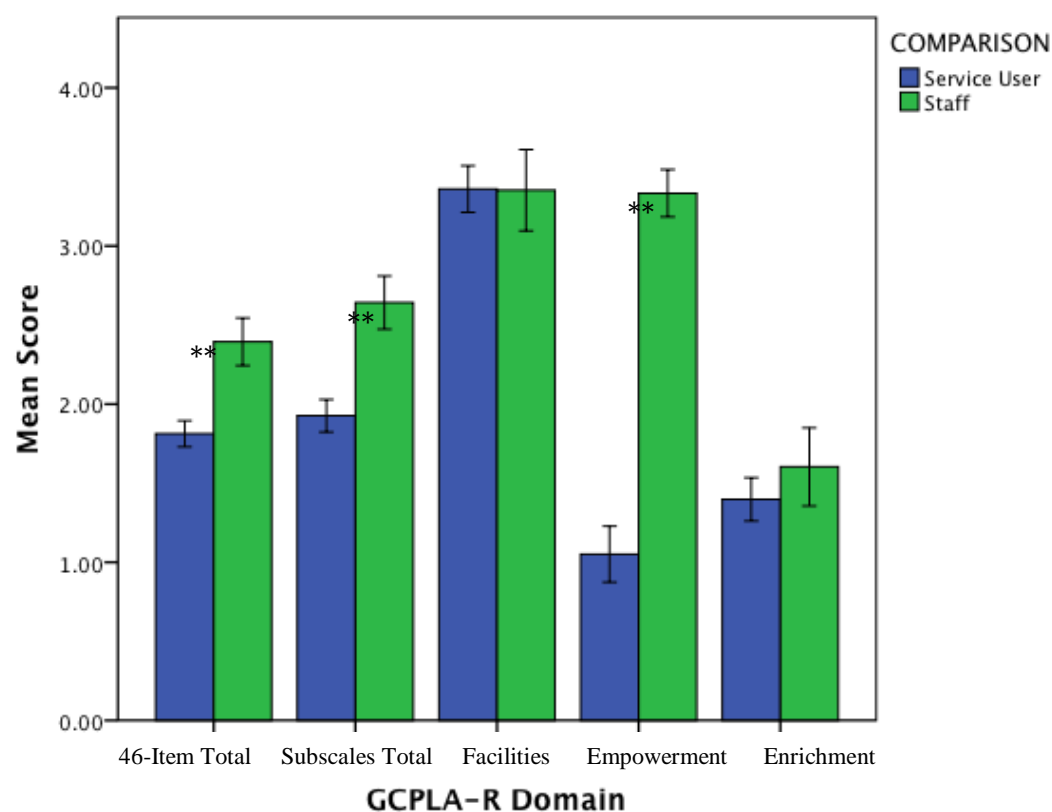
* Correlation is significant at the 0.05 level (2-tailed).

In terms of the GCPLA-R subscales, significant negative correlations were found between Activities of Empowerment and the ABC subscales of Lethargy and Stereotypy, as well as between Enrichment and the ABC subscale of Lethargy. Accessing Community Facilities was not found to be significantly correlated with any of the ABC subscales (See Table 10).

Comparing GCPLA-R scores for people with and without intellectual disabilities

Mann Whitney U-test analyses were computed to compare the scores of adults with and without (n=30) intellectual disabilities. 46-Item Total, 22-Item Total and Activities of Empowerment scores were significantly higher ($p<0.001$) in the sample of adults without learning disabilities. Figure 3 illustrates the comparison between staff and service user mean GCPLA-R scores. Significant differences between service user and staff scores are highlighted.

Figure 3: A comparison of mean GCPLA-R scores for staff and service users



**Difference between scores is significant at the 0.01 level

Error bars: 95% Confidence Interval

Demographic Analyses

Gender

Mean scores were calculated for men (n=87) and for women (n=66), for the 46-item total score, the 22-item total score and the three individual subscale scores (see Table 12). Mann Whitney U-test analysis (see Appendix 7.5) found no significant differences between GCPLA-R scores for men and women for the Total Score, the Total Subscales Score or for the three individual subscale scores.

Table 12: Mean scores according to gender

Gender		46-Item Total	22-Item Total	Accessing Community Facilities	Activities of Empowerment	Enrichment
Female	Mean	1.8006	1.9458	3.3214	1.1586	1.4116
	N	66	66	66	66	66
	SD	.53053	.63429	.80028	1.07902	.85961
Male	Mean	1.8221	1.9115	3.3881	.9697	1.3875
	N	87	87	87	87	87
	SD	.50791	.65948	1.00634	1.13045	.85356
Total	Mean	1.8128	1.9263	3.3593	1.0512	1.3979
	N	153	153	153	153	153
	SD	.51617	.64684	.92085	1.10893	.85343

Age

Bivariate Spearman's correlations (two-tailed) found that age was negatively correlated with Total GCPLA-R Scores ($r_s = -.37$, 95% CI $[-.50, -.23]$, $p < 0.001$), Total Subscales Scores ($r_s = -.43$, 95% CI $[-.55, -.30]$, $p < 0.001$), Activities of Empowerment subscale scores ($r_s = -.31$, 95% CI $[-.47, -.16]$, $p < 0.001$), and Enrichment subscale scores ($r_s = -.36$, 95% CI $[-.48, -.20]$, $p < 0.001$). Scores on the

Accessing Community Facilities subscale were not found to be significantly correlated with age.

Discussion

Summary

No psychometrically robust measure of level of community participation was in existence for adults with intellectual disabilities. The current research aimed to revise and revalidate the GCPLA. A preliminary stage involved consulting adults with intellectual disabilities, carers and relevant experts before creating the GCPLA-R. The 46-item GCPLA-R was then tested and the data relating to 153 adults with intellectual disabilities was analysed for its factor structure as well as psychometric properties. Additionally, comparisons were made between the GCPLA-R scores of people with and without (n=30) intellectual disability. The outcome of the analyses will be discussed, along with limitations and implications for future research and clinical practice.

A stable set of factors was uncovered through factor analysis, describing three different clusters of community participation activities. A final scale was produced containing three factors and 22 items. The factors were labeled 'Accessing community facilities' (explaining 22.1% of the total variance), 'Activities of empowerment' (explaining 12.5% of the variance) and 'Enrichment' (explaining 11.1% of the variance). Both the 22-item version of the GCPLA-R and the original 46-item version were tested for their psychometric properties due to uncertainty about the benefits of reducing the measure from 46 to 22 items. It was decided that the

results of the reliability and validity testing would help inform the decision about which version should be considered for publication.

The GCPLA showed good construct validity. Overall mean GCPLA-R scores (for both the 22-item and 46-item versions) correlated with other psychological constructs (challenging behaviour and adaptive behaviour) in theoretically consistent ways. Some interesting variation was found in the correlations between these constructs and the three GCPLA-R subscales. These differences will be discussed in more detail below. The GCPLA-R showed good convergent validity in that GCPLA-R scores (22-item, 46-item and all subscales) were correlated with scores on the ICI and the seven-day diary. Individuals who did not have an intellectual disability scored significantly higher on the total scores (46-item and 22-item versions) and the subscale of Activities of Empowerment, than participants who did. Test-retest and inter-rater reliability were satisfactory, as was internal consistency. No significant differences were found between GCPLA-R scores for men and women. Age was negatively correlated with all GCPLA-R Scores (22-item, 46-item and all subscales) except the Accessing Community Facilities subscale.

The first factor, 'Accessing Community Facilities' explained the largest proportion of the total variance of the GCPLA-R and contained seven items. This factor evidenced construct validity by achieving a good correlation with the conceptually related ICI. The correlation with the seven-day diary approached significance. The fact that the diaries were, in many cases, completed during the Christmas period may have produced results somewhat inconsistent with the general frequency of activities captured by the GCPLA-R. It is arguable that general activities such as accessing high

street shops and the supermarket are most likely to be different in frequency during the Christmas period. Perhaps unsurprisingly, the day-to-day activities of the Accessing Community Facilities subscale (such as going to the supermarket, the post office or the pub) did not increase or decrease with age. Levels of perceived 'challenging' behaviour (as measured by the ABC) did not significantly correlate with the degree to which people were accessing these commonplace aspects of community life. Participants with higher levels of adaptive skills in the Personal and Community Self Sufficiency subscales of the sABS, scored significantly higher on the Accessing Community Facilities subscale.

The second factor 'Activities of Empowerment' explained the second largest proportion of the total variance of the GCPLA-R and contained six items. It evidenced strong construct validity by achieving a good correlation with the ICI as well as the seven-day diary. In terms of perceived 'challenging' behaviour, lower scores on the ABC subscales of Lethargy and Stereotypy were correlated with higher Activities of Empowerment subscale scores. Participants with higher levels of adaptive skills in each of the three components of the sABS, scored significantly higher on the Activities of Empowerment subscale. Activities of Empowerment was the only subscale that produced significantly different results for people with and without intellectual disabilities. This subscale produced the lowest mean score (see Figure 3), strikingly lower than adults without intellectual disabilities. This finding is discussed in further detail in the Key Findings section below.

The third factor 'Enrichment' explained only slightly less variance than the second factor and contained nine items. This factor evidenced construct validity by achieving

a good correlation with the ICI as well as the seven-day diary. Higher scores on the Enrichment subscale were also significantly correlated with lower scores on the Lethargy ABC subscale. The subscale of Enrichment had a negative correlation (approaching significance using a conservative two-tailed test) with the sABS subscale of Personal Self-Sufficiency, suggesting that greater levels of self-sufficiency may actually be associated with lower levels of Enrichment. This is discussed further in the Key Findings section below.

The preliminary analyses rejected nine activities and the factor analysis rejected a further fifteen. While the factor analysis suggested retaining only 22 items in the final measure, the authors were cautious about doing so. When dealing with frequency data, factor analysis clusters together activities undertaken with similar frequency. While the rejected activities may not ‘fit’ with the retained factors in terms of participants’ current lifestyles, there is a strong argument for not simply accepting the status quo, and rather allowing the GCPLA-R to account for the possibility that the community participation of adults with intellectual disability may increase. For this reason the psychometric properties of both the original 46-item GCPLA-R and the 22-item (sum of the three factors) were examined.

46-item or 22-item GCPLA-R?

In terms of reliability, the 46-item and 22-item versions were largely very similar in their strength. In terms of inter-rater reliability, the 22-item GCPLA-R only approached a significant correlation coefficient. The correlation was only slightly lower than for the 46-item total. In general, the correlation coefficients were not as high for inter-rater reliability as for test re-test reliability and this may have been due,

at least in part, to the two raters frequently filling-out questionnaires either side of the Christmas period, or during the Christmas period, when people's activity levels are likely to be out of the ordinary.

In terms of content validity the 22-item version did not include all ICF domains, with Religion and Spirituality, Community Life and Particular Interpersonal Relationships no longer covered. The 46-item GCPLA-R was developed in consultation with service users and experts. The deletion of 24 items to create the 22-item version would not be in accordance with many of the views of the focus group members. In order to maintain content validity the authors chose to retain the 46 items of the GCPLA-R but to include within the scoring the facility to calculate the items within the subscales.

Key findings and implications for future research

Both the 22-item and 46-item total scores as well as two of the subscale scores were significantly negatively correlated with age. Only the commonplace activities of the Accessing Community Facilities subscale were not associated with age. Ashman, Hulme and Suttie (1990) suggest that the ageing process and the legacy of growing up in an era of institutions and increased discrimination has inflicted greater restrictions on older people with intellectual disability than would be considered acceptable for their younger peers. They highlight increasing mobility problems as well as a reduction of opportunities to interact with local people and to use community facilities independently. The findings reported here highlight a need to examine the community participation of this population and consider how best to support people to participate as much as they wish.

Previous research has highlighted the difference in community participation between people with and without intellectual disability (Verdonschot et al., 2009). However, perhaps due to the lack of sensitivity of existing measures, this distinction between different types of activities has not been reported. This study found that only Activities of Empowerment were participated in significantly less by adults with intellectual disabilities, and the difference found was striking. This suggests that people with intellectual disabilities are not being sufficiently supported to undertake important activities such as personal banking, gaining employment and assisting others that would seem fundamental to cultivating a sense of self-sufficiency and usefulness. Activities such as going to work, personal banking, internet use and social networking could perhaps not be easily supported via a group outing or activity, the way in which many support services facilitate activities falling within the subscales of Accessing Community Facilities and Enrichment. Due to the small sample size of the staff comparison group (n=30), who may not have been representative of the wider population of people without intellectual disability, this finding needs to be replicated before any conclusions can be drawn. However, this represents an interesting step forward in increasing our understanding of which aspects of community participation adults with intellectual disabilities may benefit from being supported and encouraged with. If replicated, this finding suggests that support services need to consider carefully how to facilitate community participation at the individual level.

GCPLA-R scores were related to adaptive behaviours and ‘challenging’ behaviours in theoretically consistent ways. In line with Baker’s (2000) findings, GCPLA-R scores were negatively correlated with perceived levels of ‘challenging’ behaviour. Only the

subscale of Accessing Community Facilities did not follow this association. The activities within this subscale might be considered to reflect the types of activities routinely facilitated by support services and offered to all service users (e.g. going to a supermarket, high street shop or café). This finding suggests that individuals exhibiting challenging behaviour are not having their community participation needs met. Ironically, behaviours that challenge can be understood as an attempt to get needs met (Hastings et al., 2013). It is clear that more needs to be done to understand and support the community participation needs of people exhibiting challenging behaviours.

Also in line with previous research (e.g. Baker, 2000; Chou, Lin, Pu, Lee & Chang, 2008; Heller, Miller & Factor, 1998), higher adaptive skills were associated with higher GCPLA-R scores. This consistent body of results showing that people with lower levels of adaptive behaviour tend to participate less in the local community suggests that more needs to be done to encourage and support these individuals. The subscale of Enrichment did not follow this trend and instead correlated negatively with the adaptive behaviour subscale of Self-Sufficiency. This is reminiscent of Hawkins and Freeman's (1993) finding that the 'Leisure Activity Participation Index' was negatively correlated with social communication skills and community living skills, which they suggest may be caused by increased self-determination of responders with higher adaptive skills. This implies that service users able to exercise their free choice may choose not to actively participate. This links to Cummins and Lau's (2003) argument that overzealously facilitating community integration for people with intellectual disabilities has the potential to be stressful rather than beneficial. Cummins and Lau caution that people should be in control of their own

level of exposure, and not be over-encouraged by family or support staff to take part in activities in order to be more 'normal'. It is recommended that services use a measure of service users' choice alongside the GCPLA-R.

Limitations

Order effects were not controlled for during the administration of measures and GCPLA-R items. Future studies could examine the scale using a mixed order.

The sample of adults with intellectual disabilities included a majority of participants between the ages of 25 and 65 and contained significantly more male than female participants. The ethnic diversity of the sample was also not representative of the general population in the UK, reducing the generalisability of the findings. Future studies should aim to use a more representative sample from across the UK. It should be noted that the service's policy regarding the recording of residents' ethnicity was to ask the clients what they felt their ethnicity was. The service manager pointed out that they often found residents identified as White British despite one or both of their parents belonging to other ethnic groups. The severity of intellectual disability was not recorded for the participants. The incorporation of the sABS scores gives an overview of participants' abilities. However information about the degree of diagnosed intellectual disability would have provided a further basis of comparison between individual scores and the reference data for future clinicians and researchers.

The sample size was considered adequate for the analyses performed, however researchers have argued that factor analysis is more effectively applied to samples of

300 and above (Field, 2013). Future studies should aim to test the factor structure of the GCPLA-R on a larger sample.

Some staff respondents reported that the wording of the ABC was out-dated as well as pejorative; i.e. asking staff whether behaviour was a 'problem'. A note was added to the questionnaire packs encouraging staff to consider whether the behaviour was present rather than whether it was a problem. Anecdotally, it appeared that some respondents filled in the questionnaire indicating that they did not personally perceive the behaviour to be problematic. This may have led to under-reporting of behaviours that are often considered 'challenging'. The ABC was chosen as it is a widely used measure within research. However, it may have been wiser to select a measure that did not employ language so inconsistent with the values and approach of modern day services for adults with intellectual disabilities.

Some of the reported time intervals between test and retest and between raters were longer than might have been ideal. This was at least partially due to the data collection occurring over the Christmas period, with many staff respondents and service users taking holidays and visiting family, affecting typical activity levels. It seems likely that inter-rater agreement and correlation with the 7-day diary might have been higher if the data had not been collected over the Christmas period and with such time delays.

The GCPLA-R uses one Likert scale to measure activities that have markedly different natural frequencies. For example, it might be expected that somebody would

see a doctor only a few times a year but go to the supermarket every week. Despite this flaw, the researchers felt that using one Likert scale allowed optimum ease of use.

Conclusion

A psychometrically robust measure of the level of community participation was needed in order that services could identify individuals requiring further support and so that needs did not go unmet. The GCPLA-R has emerged as a psychometrically strong measure of community participation. By retaining the 46 items identified in collaboration with service users and relevant experts, the GCPLA-R has strong face and content validity, covering all nine ICF domains of community participation. Three stable factors emerged through factor analysis. Scores on the GCPLA-R related to other psychological constructs in ways that were consistent with theory and were correlated with scores on comparable measures. Future clinicians and researchers will interpret GCPLA-R subscale scores as well as a total score, allowing a richer understanding of individual profiles of community participation.

References

- Ager, A. (1998) The BILD Life Experiences Checklist. British Institute of Learning Disabilities, Kidderminster.
- Aman M. G., Singh N. N., Stewart A. W. & Field C. J. (1985a) The aberrant behavior checklist: a behaviour rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, 89, 485–91.
- Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985b). Psychometric characteristics of the aberrant behavior checklist. *American journal of mental deficiency*, 89(5), 492.
- Aman, M. G. (2012). Aberrant Behavior Checklist: Current identity and future developments. *Clin Exp Pharmacol*, 2(3), 2161-1459. <https://doi.org/10.4172/2161-1459.1000e114>
- American Association on Intellectual and Developmental Disabilities (2016). Retrieved on 22/11/2016 from:
<https://aaidd.org/intellectual-disability/definition#.WDSeAyOLTPA>
- Ashman, A. F., Hulme, P., & Suttie, J. (1990). The life circumstances of aged people with an intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, 16(4), 335-347. <https://doi.org/10.1080/07263869000034151>

- Baker, P. A. (2007). Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20(2), 105-109. <https://doi.org/10.1111/j.1468-3148.2006.00313.x>
- Baker, P. A. (2000). Measurement of community participation and use of leisure by service users with intellectual disabilities: The Guernsey Community Participation and Leisure Assessment (GCPLA). *Journal of Applied Research in Intellectual Disabilities*, 13(3), 169-185. <https://doi.org/10.1046/j.1468-3148.2000.00015.x>
- Baglin, J. (2014). Improving Your Exploratory Factor Analysis for Ordinal Data: A Demonstration Using FACTOR. *Practical Assessment, Research and Evaluation*. 9(5), 2.
- Beadle- Brown, J., Hutchinson, A., & Whelton, B. (2012). Person- Centred Active Support—Increasing Choice, Promoting Independence and Reducing Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 291-307. <https://doi.org/10.1111/j.1468-3148.2011.00666.x>
- Bigby, C. (2004). *Ageing with a Lifelong Disability: a guide to practice, program, and policy issues for human services professionals*. Jessica Kingsley Publishers.
- British Psychological Society. (2009). *Code of Ethics and Conduct*. Guidance by the Ethics Committee of the British Psychological Society. Leicester, UK: British Psychological Society.

Chang, F. H., Coster, W. J., & Helfrich, C. A. (2013). Community participation measures for people with disabilities: A systematic review of content from an international classification of functioning, disability and health perspective. *Archives of physical medicine and rehabilitation*, 94(4), 771-781.
<https://doi.org/10.1016/j.apmr.2012.10.031>

Chou, Y. C., Lin, L. C., Pu, C. Y., Lee, W. P., & Chang, S. C. (2008). Outcomes and costs of residential services for adults with intellectual disabilities in Taiwan: A comparative evaluation. *Journal of Applied Research in Intellectual Disabilities*, 21(2), 114-125.
<https://doi.org/10.1111/j.1468-3148.2007.00373.x>

Chou, Y. C., Harman, A. D., Lin, C. J., Lee, W. P., Chang, S. C., & Lin, M. L. (2011). Outcome evaluation of active support training in Taiwan. *Research in developmental disabilities*, 32(3), 1130-1136. <https://doi.org/10.1016/j.ridd.2011.01.011>

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Second Edition. Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.
<https://doi.org/10.4324/9780203771587>

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of applied research in intellectual disabilities*, 16(2), 145-157.
<https://doi.org/10.1046/j.1468-3148.2003.00157.x>

Dziuban, C. D., & Shirkey, E. C. (1974). When is a correlation matrix appropriate for factor analysis? Some decision rules. *Psychological bulletin*, 81(6), 358.
<https://doi.org/10.1037/h0036316>

Emerson, E. (1995). *Challenging behaviour: Analysis and intervention in people with learning disabilities*. Cambridge University Press, 40 West 20th Street, New York, NY 10011-4211. <https://doi.org/10.1017/cbo9780511543739.001>

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, 39(2), 175-191. <https://doi.org/10.3758/bf03193146>

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. Sage. DOI: 10.1024/1012-5302/a000397

Fleiss, J. L. (1981). Balanced incomplete block designs for inter-rater reliability studies. *Applied Psychological Measurement*, 5(1), 105-112.
<https://doi.org/10.1177/014662168100500115>

Garson, D. G. (2008). *Factor Analysis: Statnotes*. North Carolina State University Public Administration Program.

Gorsuch, R. L. (1983). *Factor analysis* (2nd ed.). Hillsdale, NJ: Erlbaum.

Guadagnoli, E. & Velicer, W. (1988) Relation of sample size to the stability of component patterns. *Psychological Bulletin* 103 265-275. <https://doi.org/10.1037//0033-2909.103.2.265>

Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., Noone, S.J. & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. *International Journal of Positive Behavioural Support*, 3(2), 5-13.

Hatton, C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Perry, J., Felce, D., Lowe, K., Walsh, P.N., Linehan, C. and Hillery, J., (2001). The adaptive behavior scale-residential and community (part I): towards the development of a short form. *Research in developmental disabilities*, 22(4), pp.273-288.
[https://doi.org/10.1016/s0891-4222\(01\)00072-5](https://doi.org/10.1016/s0891-4222(01)00072-5)

Heller, T., Miller, A. B., & Factor, A. (1998). Environmental characteristics of nursing homes and community- based settings, and the well- being of adults with intellectual disability. *Journal of Intellectual Disability Research*, 42(5), 418-428.
<https://doi.org/10.1046/j.1365-2788.1998.00155.x>

Hawkins, B. A., & Freeman, P. A. (1993). Correlates of self- reported leisure among adults with mental retardation. *Leisure Sciences*, 15(2), 131-147.
<https://doi.org/10.1080/01490409309513193>

Hutcheson, G., & Sofroniou, N. (1999). *The multivariate social scientist: Introductory statistics using generalized linear models*. Thousand Oaks, CA: Sage Publications.
<https://doi.org/10.4135/9780857028075>

Kaiser, H. F., & Rice, J. (1974). Little Jiffy, Mark IV. Educational and Psychological Measurement, 34, 111-117. <https://doi.org/10.1177/001316447403400115>

Kendall, M. G. & Stuart A. (1958). The Advanced Theory of Statistics, Volume 1. London: Griffin.

Kline, P. (1979). Psychometrics and psychology. London: Academic Press.

MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong S. (1999). Sample size in factor analysis. Psychological Methods, 4, 84-99. <https://doi.org/10.1037//1082-989x.4.1.84>

Marshburn, E. C., & Aman, M. G. (1992). Factor validity and norms for the Aberrant Behavior Checklist in a community sample of children with mental retardation. Journal of autism and developmental disorders, 22(3), 357-373. <https://doi.org/10.1007/bf01048240>

Mazza, G. L., Enders, C. K., & Ruehlman, L. S. (2015). Addressing item-level missing data: A comparison of proration and full information maximum likelihood estimation. Multivariate behavioral research, 50(5), 504-519. <https://doi.org/10.1080/00273171.2015.1068157>

Myers F., Ager A., Kerr P. & Myles S. (1998) Outside looking in? Studies of the community integration of people with learning disabilities. Disability and Society. 13, 389–413. <https://doi.org/10.1080/09687599826704>

Nihira K., Foster R., Shellhaus M. & Leland H. (1974) AAMD Adaptive Behavior Scale.

American Association on Mental Deficiency, Washington, DC.

https://doi.org/10.1007/springerreference_184209

Nihira, K., Leland, H., & Lambert, N. (1993a). Adaptive behavior scale-residential and community (second edition): examination booklet. Austin, TX: PRO-ED.

Nihira, K., Leland, H., & Lambert, N. (1993b). AAMR adaptive behavior scale-residential and community (second edition): examiner's manual. Austin, TX: PRO-ED.

Raynes, N. V., Pratt, M. W., & Roses, S. (1979). Organisational structure and the care of the mentally retarded. Croom Helm, London

Raynes, N. V. & Sumpton, R.C. (1986). Follow up study of 448 people who are mentally handicapped. Final report to the DHSS. Manchester, The University, Department of Social Policy.

Richman, D. M., Barnard- Brak, L., Bosch, A., Thompson, S., Grubb, L., & Abby, L. (2013). Predictors of self- injurious behaviour exhibited by individuals with autism spectrum disorder. Journal of Intellectual Disability Research, 57(5), 429-439.
<https://doi.org/10.1111/j.1365-2788.2012.01628.x>

Rojahn, J., & Helsel, W. J. (1991). The Aberrant Behavior Checklist with children and adolescents with dual diagnosis. Journal of Autism and Developmental Disorders, 21(1), 17-28. <https://doi.org/10.1007/bf02206994>

- Seager M. J. (1987). Community participation and life satisfaction amongst adults with a mental handicap who live in the community. MPhil Thesis, University of Edinburgh, Edinburgh.
- Stevens, J. P. (1992). Applied multivariate statistics for the social sciences (2nd edition). Hillsdale, NJ:Erlbaum.
- Taylor, M. A., & Amir, N. (1994). The problem of missing clinical data for research in psychopathology: some solution guidelines. *The Journal of nervous and mental disease*, 182(4), 222-229. <https://doi.org/10.1097/00005053-199404000-00006>
- Taylor-Roberts, L.C. (2016). A review of community participation measures for people with intellectual disabilities. Unpublished doctoral research project. Salomons. Canterbury Christchurch University. Department of Psychology
- Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303-318. <https://doi.org/10.1111/j.1365-2788.2008.01144.x>
- World Health Organization. (2001). International Classification of Functioning, Disability and Health: ICF. World Health Organization.

Appendices

Appendix 1: International Classification of Functioning domains of Community Participation

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Appendix 2: The original GCPLA

**THE GUERNSEY COMMUNITY PARTICIPATION
AND LEISURE ASSESSMENT**

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Appendix 3: Information sheets and consent forms for focus groups

Information sheet and consent form (non-adapted version)

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Revision and revalidation of the Guernsey Community Participation and Leisure Assessment

Participant information sheet for staff, carers, service users and professionals invited to join a focus group

Information Sheet version 2; 30.05.13

This form is for staff, carers, service users and professionals who are familiar with the Guernsey Community Participation and Leisure assessment (GCPLA) and/or are likely to have some insight in to the community participation and leisure activities of adults with learning disabilities living in staffed accommodation. This form will explain why we are interested in the amount individuals with learning disabilities participate in the local community and take part in leisure activities.

Being involved in this research will involve you joining a focus group consisting of staff, carers, service users and professionals. At the focus group the facilitators will lead a discussion about how we can improve the GCPLA; a questionnaire which measures the community participation and leisure activities of adults with learning disabilities. After reading this information sheet you will be invited to sign a consent form. You do not have to take part in the project at all, but if you would like to take part then your signature is required.

Introduction

This research is being conducted by Laura Taylor Roberts, a Trainee Clinical Psychologist at Canterbury Christ Church University. Laura is supervised by Dr Peter Baker, Clinical Psychologist.

Laura is interested in how much adults with learning disabilities participate in their local community and take part in leisure activities. She is interested in this because research has shown that participation in community and leisure activities by people with a learning disability encourages their inclusion in the community, improves how they feel about their quality of life and contributes to their development of adaptive skills.

Being able to measure the amount a person participates in their community and takes part in leisure activities is therefore very useful in helping services to understand and respond to the needs of their service users and develop and improve their practice.

In order for services to measure the community participation and leisure of their service users, they need a good, usable tool which can capture this information and turn it in to a number or score which can then be compared, discussed and improved upon.

Research has suggested that the tools that already exist are not good enough. Laura hopes to update and improve the GCPLA – a tool that is already used by services for adults with learning disabilities in this area.

Laura would appreciate your help in joining the focus group to discuss which ways the GCPLA might best be improved. If you are not familiar with the GCPLA, that does not matter. We would very much appreciate any insights you have about community participation and leisure activities of adults with learning disabilities.

Taking part and your right to withdraw

You are being invited to take part in this project because you are either a) somebody who has experience of living with a learning disability, b) somebody who supports an adult with a learning disability, c) somebody who works with adults with learning disabilities.

Your participation in this project is entirely voluntary. If you choose not to participate then there will be no consequence.

If you change your mind about participating in the project, then you have the right to withdraw at any time by letting Laura or her supervisor Dr Peter Baker know. You do not have to give a reason. You can choose to withdraw even after you have taken part in the focus group. We would plan to keep the data that you had supplied up to that point unless you request that we didn't.

Procedures

If you agree to take part, you will be asked to attend a focus group where we will discuss the GCPLA and, more generally, the reality of community participation and leisure activities for adults with learning disabilities. The focus group would be expected to take about 1.5 hours. The discussion will be recorded using an audio recorder so that Laura can go back through the discussion and draw out key points that were discussed. Anything that you say in the focus group is confidential and no one else except the people involved in the project will have access to the information. General themes and points that emerge from the discussion will be used to update and improve the GCPLA. The data from the focus group will be kept for 10 years and then destroyed.

Confidentiality

You will not be asked to provide any identifying information about yourself or anybody else. The audio recording of the focus group will be kept on an encrypted, password protected device within the Clinical Psychology department at Canterbury Christchurch University and destroyed after 10 years.

The identity of all focus group members will remain anonymous. The focus group itself will be bound by a confidentiality agreement so that members of the group will not discuss anything outside of the group.

The information you provide will be put together with other people's responses and considered together as a whole. Laura will use all of this information to improve and update the GCPLA.

Risks and Benefits

You do not have to say anything during the focus group. You do not have to give any reason for not joining in parts of the discussion or for refusing to take part.

We do not envisage there being any particular risks in taking part in this research. There will be no direct benefit to you, but your participation is likely to help Laura and Dr Peter Baker to develop a useful measure of community participation and leisure. A good, reliable measure will help adults with learning disabilities to have their needs understood and met. It will allow services, where necessary, to take steps to help increase the community participation and leisure of their service users. This is likely to improve their quality of life and social inclusion.

Who to Contact

You can contact Laura or Peter if you have any concerns or questions about the nature of the study.

Laura – Telephone – 07889 881884
Email – l.c.taylor-roberts174@canterbury.ac.uk

Peter – Telephone – 01424 726551
Email – Peter.baker@sussexpartnership.nhs.uk

You can contact Professor Paul Camic at the university if you have any complaints about the study.

Telephone- 03330 117 114
Email – Paul.Camic@Canterbury.ac.uk

Study Number:

Participant Identification Number:

CONSENT FORM

Title of Project: **Revision and revalidation of the Guernsey Community Participation and Leisure Assessment**

Name of Researcher: **Laura Taylor-Roberts**

i. Please initial all boxes

1. I confirm that I have read and understand the information sheet dated (version2; 30.05.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Laura Taylor-Roberts

Name of person
taking consent

Date

Signature

Adapted (in consultation with a SAGE member) version of information sheet and consent form

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Revision and testing of the GCPLA (Guernsey Community Participation and Leisure Assessment)

Participant information sheet for people invited to join the focus group

Information Sheet version 3: 24.07.13

If it would be helpful, please ask somebody to read this information to you. Please contact Laura (telephone number at the end of this information sheet) if you would like her help with this, or if there is anything you do not understand.

This form is for people who are likely to have some thoughts about community involvement and leisure activities of adults with learning disabilities. This form will explain why we are interested in the amount individuals with learning disabilities are involved in their local community and take part in leisure activities.

Being involved in this research will involve you joining a focus group consisting of staff, carers, service users and professionals. At the focus group the facilitators will lead a discussion about how we can improve the GCPLA; a questionnaire that measures the community involvement and leisure activities of adults with learning disabilities. The focus group will be confidential, please read on to find out more.

After reading this information sheet you will be invited to sign a consent form. You do not have to take part in the project at all, but if you would like to take part then your signature is required.

Introduction

This research is being conducted by Laura Taylor Roberts, a Trainee Clinical Psychologist at Canterbury Christ Church University. Laura is supervised by Dr Peter Baker, Clinical Psychologist.

Laura is interested in how much adults with learning disabilities are involved in their local community and take part in leisure activities. She is interested in this because research has shown that involvement in community and leisure activities by people with a learning disability has many benefits. It encourages their feeling of being part of the community, improves how they feel about their quality of life and contributes to their development of daily living skills.

Being able to measure the amount a person is involved in their community and takes part in leisure activities is very useful in helping services to understand and respond to the needs of service users and develop and improve their practice.

In order for services to measure the community involvement and leisure of their service users, they need a good, usable tool, which can capture this information. The tool can turn this information in to a number, which can then be compared, discussed and improved upon.

Research has suggested that the tools that already exist are not good enough. Laura hopes to update and improve the GCPLA – a tool that is already used by services for adults with learning disabilities in this area.

Laura would appreciate your help in joining the focus group to discuss which ways the GCPLA might best be improved. If you do not know about the GCPLA, that does not matter. We would very much appreciate any thoughts you have about community involvement and leisure activities of adults with learning disabilities.

Taking part and your right to withdraw

You are being invited to take part in this project because you are either a) somebody who has experience of living with a learning disability, b) somebody who supports an adult with a learning disability, c) somebody who works with adults with learning disabilities.

Your involvement in this project is entirely voluntary. If you choose not to be involved it does not matter and nothing will change.

If you change your mind about being involved in the project, then you have the right to withdraw at any time by letting Laura or her supervisor Dr Peter Baker know. You do not have to give a reason. You can choose to withdraw even after you have taken part in the focus group. We would plan to keep the information that you had supplied up to that point unless you request that we didn't.

Procedures

If you agree to take part, you will be asked to attend a focus group where we will discuss the GCPLA and, more generally, the reality of community involvement and leisure activities for adults with learning disabilities. The focus group would be expected to take about one and a half hours. The discussion will be recorded using an audio recorder so that Laura can go back through the discussion and draw out key points that were discussed. Anything that you say in the focus group is confidential and no one else except the people involved in the project will have access to the information. General themes and points that emerge from the discussion will be used to update and improve the GCPLA. The information from the focus group will be kept for 10 years and then destroyed.

Confidentiality

You will not be asked to provide any identifying information about yourself or anybody else. The audio recording of the focus group will be kept on a password protected device within the Clinical Psychology department at Canterbury Christchurch University and destroyed after 10 years.

The identity of all focus group members will remain anonymous. The focus group itself will be bound by a confidentiality agreement so that members of the group will not discuss anything outside of the group.

The information you provide will be put together with other people's responses and considered together as a whole. Laura will use all of this information to improve and update the GCPLA.

Risks and Benefits

You do not have to say anything during the focus group. You do not have to give any reason for not joining in parts of the discussion or for refusing to take part.

We do not expect there to be any particular risks in taking part in this research. There will be no direct benefit to you, but your involvement is likely to help Laura and Dr Peter Baker to develop a useful measure of community participation and leisure. A good, reliable measure will help adults with learning disabilities to have their needs understood and met. It will allow services, where necessary, to take steps to help increase the community involvement and leisure of their service users. This is likely to improve their quality of life and their feeling that they are part of the community.

Who to Contact

You can contact Laura or Peter if you have any concerns or questions about the study.

Laura – Telephone – 07889 881884
Email – l.c.taylor-roberts174@canterbury.ac.uk

Peter – Telephone – 01424 726551
Email – Peter.baker@sussexpartnership.nhs.uk

You can contact Professor Paul Camic at the university if you have any complaints about the study.

Telephone- 03330 117 114
Email – Paul.Camic@Canterbury.ac.uk

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Study Number:

Participant Identification Number:

CONSENT FORM

Title of Project: **Revision and revalidation of the Guernsey Community Participation and Leisure Assessment**

Name of Researcher: **Laura Taylor-Roberts**

ii. Please tick all boxes



1. I confirm that I have read and understand the information sheet dated (version2; 30.05.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

Name of participant

Date

Signature

Laura Taylor-Roberts
Name of person
taking consent

Date

Signature

Appendix 4: University ethical confirmation to proceed

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Appendix 5: Information sheets for test stage

Information sheet for main stage of testing

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Revision and Revalidation of the Guernsey Community Participation and Leisure Assessment

Participant information sheet for staff and carers supporting an adult with a learning disability

Information Sheet version 2; 30.11.14

This form is for staff or carers who are supporting an adult with a learning disability who lives in staffed accommodation. We will explain why we are interested in the amount individuals with learning disabilities participate in the local community and take part in leisure activities.

A note on Consent

Being involved in this research will involve you providing information about an adult with a learning disability. After reading this information sheet you will be invited to sign a consent form.

- If you, as somebody who knows this person well, feel that they would not be able to fully understand this research study and consent to your participation, then please read this information sheet and sign the consent form provided if you are happy to take part.
- However, if you think that the person would be able to understand the information in this information sheet then please read or give it to them. If, after considering the information, they are happy for you to participate in this research using anonymous information about them, then please ask them to join you in signing Consent Form B (please contact Laura Taylor-Roberts to obtain Consent Form B).

You do not have to take part in the project at all, but if you would like to take part then your signature is required.

Introduction

This research is being conducted by Laura Taylor Roberts, a Trainee Clinical Psychologist at Canterbury Christ Church University. Laura is supervised by Dr Peter Baker, Clinical Psychologist.

Laura is interested in how much adults with learning disabilities participate in their local community and take part in leisure activities. She is interested in this because research has shown that participation in community and leisure activities by people with a learning disability encourages their inclusion in the community, improves how they feel about their quality of life and contributes to their development of adaptive skills.

Being able to measure the amount a person participates in their community and takes part in leisure activities is therefore very useful in helping services to understand and respond to the needs of their service users and develop and improve their practice.

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

In order for services to measure the community participation and leisure of their service users, they need a good, usable tool which can capture this information and turn it into a number or score which can then be compared, discussed and improved upon.

Research has suggested that the tools that already exist are not good enough. Laura has developed a questionnaire that she hopes will improve upon the tools that already exist.

Laura would appreciate your help in filling out this newly developed questionnaire so that she can check whether it is an accurate and reliable measure of community participation and leisure.

Taking part and your right to withdraw

You are being invited to take part in this project because you are somebody who supports an adult with a learning disability and knows them well enough to answer questions about their community participation and leisure activities.

Your participation in this project is entirely voluntary. If you choose not to participate then there will be no consequence.

If you change your mind about participating in the project, then you have the right to withdraw at any time by letting Laura or her supervisor Dr Peter Baker know. You do not have to give a reason. You can choose to withdraw even after you have given in the questionnaire. We would plan to keep the data that you have supplied up to that point unless you request that we didn't.

Procedures

If you agree to take part, you will be asked to fill out a questionnaire about the recent activities of an individual with a learning disability who you know. Additionally, you will be asked to fill out some other questionnaires about the same individual. The questionnaires should take no more than 30 minutes to fill out. Your answers to the questionnaires are confidential, and no one else except the people involved in the project will have access to the information. The questionnaire will be anonymous so that only you will know the identity of the person about whom you are answering the questions. The questionnaire will be kept for 10 years and then shredded.

Some people who participate will be asked if they are willing to complete the same questionnaire again a few weeks later. Some participants will be asked to fill out an activity diary in addition to the questionnaire.

Confidentiality

You will not be asked to provide any identifying information about the person with a learning disability or yourself. Each questionnaire will have a number on it instead of a name. All questionnaires will be kept in a locked cupboard.

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

The information you provide will be put together with other people's responses and considered together as a whole. Laura will use all of this information to check that each item of the questionnaire is measuring the same thing and whether it is a reliable measure.

Risks and Benefits

You do not have to answer any items on the questionnaire if you don't wish to do so. You do not have to give any reason for not responding to any question, or for refusing to take part.

We do not envisage there being any particular risks in taking part in this research. There will be no direct benefit to you or the person with a learning disability who you support, but your participation is likely to help Laura and Dr Peter Baker to develop a useful measure of community participation and leisure. A good, reliable measure will help adults with learning disabilities to have their needs understood and met. It will allow services, where necessary, to take steps to help increase the community participation and leisure of their service users. This is likely to improve their quality of life and social inclusion.

Who to Contact

You can contact Laura or Peter if you have any concerns or questions about the nature of the study.

Laura – Telephone – 07889 881884
Email – l.c.taylor-roberts174@canterbury.ac.uk

Peter – Telephone – 01424 726551
Email – P.A.Baker@Kent.ac.uk

You can contact Professor Paul Camic at the university if you have any complaints about the study.

Telephone- 03330 117 114
Email – Paul.Camic@Canterbury.ac.uk

Information sheet for comparison stage

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Revision and revalidation of the Guernsey Community Participation and Leisure Assessment

Participant information sheet for individuals who are willing to take part in the comparison stage of our research

Information Sheet version 4; 12.09.14

This form is for people who may be interested in taking part in the comparison stage of our research. We are interested in the amount individuals with learning disabilities participate in the local community and take part in leisure activities. We have developed a questionnaire to measure this. We would like to try using our questionnaire to measure the community participation and leisure activities of people who do not have a learning disability. This information sheet explains why we are interested in this and how you could help us with our research.

Being involved in this research will involve you providing information about the sorts of activities you are involved in and how much you participate in your local community. After reading this information sheet you will be invited to sign a consent form. You do not have to take part in the project at all, but if you would like to take part then your signature is required.

Introduction

This research is being conducted by Laura Taylor Roberts, a Trainee Clinical Psychologist at Canterbury Christ Church University. Laura is supervised by Dr Peter Baker, Clinical Psychologist.

Laura is interested in how much adults with learning disabilities participate in their local community and take part in leisure activities. She is interested in this because research has shown that participation in community and leisure activities by people with a learning disability encourages their inclusion in the community, improves how they feel about their quality of life and contributes to their development of adaptive skills.

Being able to measure the amount a person participates in their community and takes part in leisure activities is therefore very useful in helping services to understand and respond to the needs of their service users and develop and improve their practice.

In order for services to measure the community participation and leisure of their service users, they need a good, usable tool which can capture this information and

turn it into a number or score which can then be compared, discussed and improved upon.

Research has suggested that the tools that already exist are not good enough. Laura has developed a questionnaire that she hopes will improve upon the tools that already exist.

Laura would appreciate your help in filling out this newly developed questionnaire so that she can check whether it is an accurate and reliable measure of community participation and leisure.

Taking part and your right to withdraw

You are being invited to take part in this project because you do not have a learning disability. Your participation in this project is entirely voluntary. If you choose not to participate then there will be no consequence.

If you change your mind about participating in the project, then you have the right to withdraw at any time by letting Laura or her supervisor Dr Peter Baker know. You do not have to give a reason. You can choose to withdraw even after you have given in the questionnaire. We would plan to keep the data that you have supplied up to that point unless you request that we didn't.

Procedures

If you agree to take part, you will be asked to fill out a questionnaire about your recent activities. The questionnaire should take less than 10 minutes to fill out. Your answers to the questionnaire are confidential, and no one else except the people involved in the project will have access to the information. The questionnaire will be anonymous so that only you will know the identity of the person about whom you are answering the questions. The questionnaire will be kept for 10 years and then shredded.

Confidentiality

You will not be asked to provide any identifying information about yourself. Each questionnaire will have a number on it instead of a name. All questionnaires will be kept in a locked cupboard.

The information you provide will be put together with other people's responses and considered together as a whole. Laura will use all of this information to check that each item of the questionnaire is measuring the same thing and whether it is a reliable measure. By collecting information about the activities of adults who do not have a learning disability, we will be able to compare this with information about the activities of adults with learning disabilities. This will help us to see if there are any differences and whether the new questionnaire is sensitive enough to pick up on these.

Risks and Benefits

You do not have to answer any items on the questionnaire if you don't wish to do so. You do not have to give any reason for not responding to any question, or for refusing to take part.

We do not envisage there being any particular risks in taking part in this research. There will be no direct benefit to you or the person with a learning disability who you support, but your participation is likely to help Laura and Dr Peter Baker to develop a useful measure of community participation and leisure. A good, reliable measure will help adults with learning disabilities to have their needs understood and met. It will allow services, where necessary, to take steps to help increase the community participation and leisure of their service users. This is likely to improve their quality of life and social inclusion.

Who to Contact

You can contact Laura or Peter if you have any concerns or questions about the nature of the study.

Laura – Telephone – 07889 881884
Email – l.c.taylor-roberts174@canterbury.ac.uk

Peter – Telephone – 01424 726551
Email – P.A.Baker@Kent.ac.uk

You can contact Professor Paul Camic at the university if you have any complaints about the study.

Telephone- 03330 117 114
Email – Paul.Camic@Canterbury.ac.uk

Appendix 6: Consent forms for test stage

Consent form for staff who gave consent on behalf of an individual with an intellectual disability:

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: Revision and revalidation of the Guernsey Community Participation and Leisure Assessment

Name of Researcher: Laura Taylor-Roberts

**Please
initial all
boxes**

1. I confirm that I have read and understand the information sheet (version2; 30.11.14) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
<u>Laura Taylor-Roberts</u>		
Name of Person taking consent.	Date	Signature

Consent form for staff who decided that the individual with an intellectual disability had the capacity to understand the information contained in the information sheet and give informed consent themselves:

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Study Number:

Participant Identification Number for this trial:

CONSENT FORM B

Title of Project: Revision and revalidation of the Guernsey Community Participation and Leisure Assessment

Name of Researcher: Laura Taylor-Roberts

Please tick
all
boxes



1. I understand all of the information about this study. I have had the chance to think about the information and ask questions. My questions have been answered

☐

2. I understand that I don't have to give my permission for this person to answer questions about me. If I do give my permission then I am free to change my mind at any time without giving any reason.

☐

3. I agree to give my permission for this person to answer some questions about me.

☐

My name

Date

Signature

Name of person
taking part in the study

Date

Signature

Consent form for comparison stage:

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Study Number:

Participant Identification Number for this trial:

CONSENT FORM C

Title of Project: **Revision and revalidation of the Guernsey Community Participation and Leisure Assessment**

Name of Researcher: **Laura Taylor-Roberts**

Please
initial all
boxes

4. I confirm that I have read and understand the information sheet dated (version1; 30.05.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

6. I agree to take part in the above study.

☐

Name of participant

Date

Signature

Laura Taylor-Roberts

Name of person
taking consent.

Date

Signature

Appendix 7: Tables

Appendix 7.1

Table 2: Content of the two focus group discussions divided into three superordinate themes

Item specifics	Ease of use	Conceptual
Include internet access, e.g. online banking, mobile phone/laptop use, social networking, online gaming	Drop boxes for each total to make scoring easier	Discussion around supervised activities not being applicable to people with severe ID
Include looking at books/magazines	Consider re-wording frequencies. E.g. use “fortnightly” or “very infrequently”	Include internet access and computer use but don’t let technical aspects take over
Include photography?	Lots of empty space – condense form	Is it important to distinguish whether indoor leisure activities take place at home or in the community?
Remove wording of ‘cassettes’, ‘videos’ and ‘disco’. Discussion around continuing use of the word ‘disco’	Bottom of page notes are helpful	Expand travel to include own vehicles? – discussion around ‘going for a drive’ in a vehicle belonging to a residential or day service. Mixed opinions – can be helpful but can be over-used for some people who may not be benefitting from it.
Expand public transport items to include air travel - or consider amalgamating use of all public transport into one item	‘Support’ column doesn’t have to be filled in. Provide instructions on how to decide? Or delete it? Discussion around people not using it/ not finding it useful	Inclusion of solitary activities – consider excluding entirely and making measure solely about community participation. Mixed views – general consensus that solitary activities lead to “richness of life” which the GCPLA-R should be trying to capture
Include walking in the countryside as separate from walking to the local shop. Include day trip as well as holiday	Include definition of community participation in final version	Discussion around including engagement in household tasks – shift towards general measure of engagement? It would be helpful to measure ‘active involvement’ and not just ‘passivity’

Include DIY?

Discussion around whether it matters if participation is with the general public or exclusively with other service users. General feeling that ‘segregated’ activities are of worth as well as unsegregated.

Expand on adult education - Include participation in music and drama and attending college

Have space on the GCPLA-R to record what an individual’s favourite activities are in order to measure participation in these

Include employment, either paid or voluntary

Consider incorporating a ‘choice’ box to indicate whether an activity was participated in by choice. Discussion around current measures used to measure choice alongside GCPLA and possible over-complication of GCPLA-R. Discussion around subjective nature of measuring somebody’s choice by proxy and subsequent validity of this

Include political activity such as advocacy involvement or fundraising

Discussion around whether some staff and service users may consider the GCPLA a test rather than a measure. Consider including a small explanation of the GCPLA-R as a measure and not a test

Include assisting others

Consider developing a parallel measure to be used by individuals with ID rather than by proxy

Include social club

Include a ‘Planning’ box for clinical needs – to bridge the gap between the GCPLA-R and action points

Discussion around need for equilibrium and not increasing the measure to include too many items. Consider including a box for ‘Other’

GCPLA is a useful tool for facilitating reflective practice

Include nightclub.
Discussion around possible out datedness of word ‘disco’ – service users expressed the view that this word is still

Discussion around whether it should ‘count’ when a hairdresser or doctor visits the home. Mixed views. Consider rewording and combining items to create “accessing medical

current and should be included.

Where would 'music festival' fit? Consider re-wording 'Concert' item.

Remove 'go to neighbour's house'

Remove interaction with police.

Include 'Attend reviews'? Mixed views on this

Consider including 'Contact with professionals' such as social workers, osteopaths and chiropractors. Mixed views on this.

professionals"?

Discussion around whether it should be recorded how many activities were accessed through day services. Mixed views on this.

Appendix 7.2

Table 3: Eigenvalues over 1 and total variance explained

Factor	Initial Eigenvalues			Rotation Sums of Squared Loadings
	Total	% of Variance	Cumulative %	Total
1	7.074	19.119	19.119	5.060
2	3.403	9.197	28.316	3.944
3	2.756	7.448	35.764	3.201
4	1.900	5.135	40.898	4.383
5	1.733	4.684	45.582	2.191
6	1.515	4.094	49.676	1.653
7	1.490	4.027	53.703	3.112
8	1.346	3.637	57.340	1.679
9	1.270	3.433	60.772	2.445
10	1.162	3.140	63.912	1.053
11	1.090	2.947	66.859	1.598
12	1.034	2.794	69.653	1.079

Extraction Method: Principal Axis Factoring.

Appendix 7.3

Table 6: Internal Correlations of the GCPLA-R

	Accessing Community Facilities	Activities of Empowerment	Enrichment
46-Item Total	.51**	.52**	.71**
22-Item Total	.61**	.63**	.69**
Accessing Community Facilities	1	.25**	.15
Activities of Empowerment	.25**	1	.11
Enrichment	.15	.11	1

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

Appendix 7.4

Table 9. Correlations between GCPLA-R scores and sABS scores

	sABS Personal Self Sufficiency	sABS Community Self Sufficiency	sABS Personal Social Responsibility	sABS Total
46-Item Total	.181*	.241**	.330**	.245**
22-Item Total	.349**	.417**	.439**	.415**
Accessing Community Facilities	.275**	.229**	.158	.240**
Activities of Empowerment	.675**	.782**	.751**	.779**
Enrichment	-.158	-.098	-.011	-.116

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Appendix 7.5

Table 11. Mann Whitney U calculations examining differences between male and female mean scores

	GCPLA-R Total	GCPLA-R Subscales Total	Accessing Community Facilities	Activities of Empowerment	Enrichment
Mann- Whitney U	2824.000	2732.000	2594.500	2493.500	2802.500
Wilcoxon W	5035.000	6560.000	4805.500	6321.500	6630.500
Z	-.173	-.512	-1.021	-1.418	-.253
Asymp. Sig. (2-tailed)	.863	.609	.307	.156	.801

Appendix 8: Slide show of picture prompts





Appendix 9: Transcription of focus group for staff and carers

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Appendix 10: GCPLA-R

The Guernsey Community Participation and Leisure Assessment – Revised

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Revised

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Appendix 11: Seven-day diary

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Appendix 12: Feedback to participants

Faculty of Social and Applied Sciences
Clinical Psychology Doctoral Programme
Canterbury Christ Church University
Tunbridge Wells Campus

Dear all of the people who filled out questionnaires (whilst thinking about an adult with an intellectual disability who they knew well),

We would like to inform you that the research project is now finished and, **thanks to all of you**, we are now in a position to publish a new and improved questionnaire to measure the amount that people with intellectual disabilities participate in their local community.

Here is some more detailed feedback about the research project...

Research has identified community participation as an important aspect of quality of life. Research has also established that people with intellectual disabilities participate less in their local communities than people without intellectual disabilities. Despite this, prior to this project, an up to date, psychometrically robust measure of the level of community participation of adults with intellectual disabilities was not in existence.

This project aimed to bring up to date, revise and revalidate the Guernsey Community Participation and Leisure Assessment (GCPLA; Baker, 2000). Adults with intellectual disabilities, carers and relevant experts were consulted in creating a 46-item revised version of the GCPLA (the GCPLA-R). The measure was then tested by asking support staff to complete it (alongside a number of other questionnaires), whilst thinking about an individual with an intellectual disability who they knew well.

The data from 153 adults with intellectual disabilities were analysed for their factor structure (to see if the 46 GCPLA-R items could be grouped into meaningful sub categories), reliability (whether the GCPLA-R would find the same results when completed twice by the same person or by two different people) and validity (whether the GCPLA-R compared to other measures in ways that were expected based on theory and previous research).

Factor analysis found that the GCPLA-R contained three different clusters of community participation activities. These were labelled: 'Accessing Community Facilities', 'Activities of Empowerment' and 'Enrichment'. A full (46-item) and a brief (22-item) version of the scale were produced, each containing the three sub-scales. Both the 22-item and 46-item GCPLA-R were found to have satisfactory reliability. Scores on the GCPLA-R were related to perceived challenging behaviour and adaptive behaviour in ways that were expected based on previous research and theory, and were correlated with scores on comparable questionnaires.

The 46-item GCPLA-R was selected for publication as the higher number of items meant good coverage of the different aspects of community participation. Also, the deletion of 24 items would not have been in accordance with many of the views of the focus group members.

Yours sincerely,

Laura Taylor-Roberts and Peter Baker

Appendix 13: Letter to Salomons Ethics Panel

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Appendix 14: Publication guidelines for Journal of choice

Journal of Applied Research in Intellectual Disabilities

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